People with Multiple Sclerosis in South East Queensland : A Study of the Use and Cost of Mainstream Medicine and Complementary Therapies.

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"This report is submitted in partial requirement for the award of Master of Public Health at the University of Queensland."

DECLARATION

This dissertation is an original work of the author and has not been submitted for credit for any other degree or part thereof.

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ABSTRACT

Multiple sclerosis (MS) is a common, incurable, demyelinating disorder of humans which predominately affects 20-40 year olds, the majority being women. MS affects over 10,000 Australians, with a prevalence of 18/100,000 in Queensland (Hammond 1987; McLeod 1994). The demand for health services by people with MS varies with individuals and the levels of the disability experienced. The present study of 40 people with MS looks at mainstream medicine and complementary therapies accessed by people with MS and the cost of these therapies. The unmet needs and concerns of people with MS were also documented.

Results of this study show that a high percentage of the study subjects (82.5%) were users of complementary therapy as an adjunct to mainstream medicine. All study participants were users of mainstream medicine. The use of physiotherapy and the Multiple Sclerosis Society of Queensland (MSSQ) was increased as disability worsened, with unemployed persons more likely to use community health facilities than employed persons.

There was a higher use of complementary therapies by females compared with males (93% vs 54%); and by patients with the relapsing-remitting type of MS (94%) compared with secondary progressive MS (75%) or those with primary progressive MS (70%). More tertiary educated people used complementary therapies than those with no tertiary qualifications (100% vs 79%).

The cost of using complementary therapies for people with MS ranged from $5 to $725 per month ($100 median). Most people spent less than $20 on any one therapy. These findings are consistent with other studies that show the use and cost of complementary therapies in chronic incurable diseases is substantial.

Study participants were given opportunity to express issues of concern and/or unmet needs. Twenty nine of the 40 subjects (72.5%) raised issues primarily relating to problems of transportation, lack of knowledge about MS by some health professionals and difficulty in accessing services for MS sufferers and their carers. The remainder expressed no concerns or unmet needs.

In conclusion, the results of this study show that people with MS are heavy users of complementary therapies. Mainstream medical providers need to be aware of this high use of complementary therapies by people with MS and discuss the potential harm in the consumption and use of unproven treatments with the patients.

GLOSSARY OF TERMS

- Acupuncture — the insertion of hair thin needles into specific points on the body, which is a traditional part of Chinese medicine for over 2,000 years.
- Hypnotherapy and imagery — using either enhanced suggestibility, an altered state of mind and behaviour, guided imagery used with relaxation, biofeedback hypnosis, meditation.
- Massage and bodywork — massage has been used in ancient cultures for thousands of years. Some popular western massages include swedish, deep tissue, reflexology, polarity therapy, reiki, therapeutic touch, Feldenkrais and Alexander techniques.
- Biofeedback — translates skin temperature, muscle contractions, blood pressure, pulse, brain waves and other body functions into audio or video signals thereby aiding the patient to learn to control body process.
- Tai chi — a blend of exercise and energy work, by using slow arm movements that are controlled and shifting body weight from one foot to the other.
- Chiropractic therapy — began in the late 19th century using manipulation methods of protruding parts of spinal vertebrae

LIST OF ABBREVIATIONS USED

ADEC	Australian Drug Evaluation Committee
ADRAC	Adverse Drug Reactions Committee
CMEC	Complementary Medicines EValuation Committee
CNS	Central nervous system
EAE	Experimental autoimmune encephalomyelitis
EDSS	Expanded disability status scale
HIV	Human immunodeficiency virus
HLA	Human leukocyte antigen
MRI	Magnetic resonance imaging
MS	Multiple sclerosis
MSSQ	Multiple sclerosis society of Queensland
PP MS	Primary progressive MS
RR MS	Relapsing-remitting MS
SP MS	Secondary progressive MS

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Chapter 1 Introduction

There are many chronic, debilitating and incurable diseases afflicting people in society. A number of these such as arthritis, human immunodeficiency virus (HIV) infection and multiple sclerosis (MS) remain incurable and progressively disabling. These diseases are the focus of intensive research and scientific investigation, which will, in time, provide answers and better treatments for people suffering from these diseases. However, in the meantime, patients struggle for many years to cope with the burdens of their disease.

Multiple sclerosis is a common demyelinating incurable disease which predominately affects 20 - 40 year olds, the majority being women. When diagnosed with MS the person is faced with an uncertain future, with a disease which may cause moderate to severe disability. The demand for health services by people with MS varies with individuals and depends on the level of disability experienced and the emotional and personal situation of the individual (Hainsworth 1994). MS has a profound effect on the lives of individuals and also the family members and carers. From conversations with people with MS, it appears that issues relating to complementary therapy and the cost of its use, play a significant role in the lives of people with MS.

This study documents the most frequently used services, health therapy options, both mainstream and complementary, and the cost involved for people with MS.

Chapter 2 Literature Review

2.1 Multiple Sclerosis - General Overview

Multiple sclerosis (MS) is a chronic inflammatory demyelinating disease of the central nervous system (CNS) (Pender, 1995). It is the most common CNS disease of young adults and causes significant disability. A study in 1986 by Hammond et al. (1987) showed that, in Queensland, the prevalence of MS is 18/100,000. Lesions of MS were first described by Carswell in 1835 (Compston,1988), although diseases with symptoms resembling MS have been described as early as the 14th century (Adams, 1989). MS is a chronic disabling disorder which is incurable, although recently some immunological modulatory therapies have been introduced that may modify the course of the disease.

2.1.1 Clinical features of MS

MS may commence as early as the age of three years (Hanefield et al., 1991), or as late as the seventh decade, but it generally presents between the ages of 15 and 50 years (Confavreaux et al., 1980, Weinshenker et al., 1989). There appears to be a relationship between age of onset and the sex of the patient (McAlpine, 1991); in childhood MS and early-adult-onset MS, twice as many females as males develop MS. In contrast, MS presenting after the age of 40 usually affects more males than females.

The most common neurological symptoms and signs of MS are shown in Table 2.1 (McAlpine, 1991; Pender, 1995):

Table 2.1 Common neurological signs and symptoms of MS

- visual loss, due to optic neuritis.
- weakness of the lower limbs, with or without upper limb weakness.
- sensory loss or numbness of the limbs or trunk.
- sensory or unsteady gait.
- bladder and bowel disturbance.
- cognitive impairment - poor concentration, recall difficulties
- cranial nerve symptoms and signs (double vision, facial sensory disturbance)
- nystagmus

The signs and symptoms may occur in an episodic fashion with each episode being regarded as an 'attack' of MS. The clinical features of an attack of MS may remit completely or in part, may remain stationary for a prolonged period, or may progress. Some studies have shown a strong positive correlation between rapidity of onset and degree of recovery, with a lesser relationship between recovery and the severity or nature of the symptoms (McAlpine, 1991). The greater the degree of recovery from a relapse the better the expectation of remission in the next relapse.

2.1.2 Types of MS.

Several distinct types of MS are recognized on the basis of the clinical course. Classification of the types of MS is as follows. These are relapsing remitting MS (RR-MS), secondary progressive MS (SP-MS), and primary progressive MS (PP-MS). The most common and typical course is one of relapses and remissions (RR-MS). Patients with RR-MS may later develop a gradually progressive pattern of neurological deficit which is known as secondary progressive MS (SP-MS). About one-third of MS patients experience a progressive course without experiencing any obvious discrete attacks or remissions during their illness; this is known as primary progressive MS (PP-MS) (McAlpine, 1991). Patients who develop MS at a later age often present with PP-MS (Cazzullo et al., 1978; Weinshenker et al., 1989), and their prognosis is often relatively poor. For a few patients, MS takes an acute rapidly progressive course known as Marburg's disease, or acute MS (Lassmann et al., 1981) in which death occurs within three weeks to six months after the onset of the first clinical signs.

2.1.3 Pathophysiology of the neurological deficits in MS

The major cause of the neurological deficits in MS is conduction block due to primary demyelination of nerve fibres. However, loss of axons can also occur in MS (Barnes et al., 1991) and is likely to be an important cause of persistent disability. In most MS patients, pathology is restricted to the CNS myelin, in particular the optic nerves, spinal cord and cerebral white matter. However,

there is also some evidence of peripheral nervous system (PNS) involvement in a small percentage of patients with typical MS (Waksman, 1993)

2.1.4 Prognosis of MS

It is difficult to predict prognosis, however the following factors, shown in Table 2.2, suggest a poor prognosis (Clanet 1995):

Table 2.2 Factors suggesting a poor prognosis

- a progressive course from disease onset
- age at onset greater than is usual (> 40 years)
- male gender
- a short time between the first two exacerbations (attacks)
- a high frequency of exacerbations

The most common causes of death in MS are infections due to the paralysed state of the patient, unrelated disease, and occasionally suicide; death from a direct effect of MS on the nervous system is uncommon.

2.1.5 Measurement of Multiple Sclerosis Disability - The Expanded Disability Status Scale (EDSS)

The Expanded Disability Status Scale (EDSS) (Kurtzke, 1983) is a scoring system specifically designed to rate the degree of disability in a person with MS. This score concentrates on lower limb involvement and mobility. A low score (1 - 4) indicates mild disability with full ambulation; an EDSS of 5 - 6

demonstrates impairment with disability severe enough to impair full daily activities; an EDSS of 6 - 7 indicates a requirement for intermittent or unilateral support to walk about 100 metres. When a person has a higher score (7 - 10) they will require bilateral assistance or wheelchair mobility. For example a person with a score of 7.5 is unable to take more than a few steps and is essentially restricted to a wheelchair, requiring the assistance of attendants or carers for maintenance of acceptable living standards. The EDSS has been criticised because it primarily assesses lower limb function. Other tests, used less commonly, such as the Nine Hole Peg Test, evaluate upper limb motor weakness and/or sensory loss.

2.2 Causes of multiple sclerosis

The cause of MS is unknown. However it is thought that factors important in the aetiopathogenesis of MS are genetic predisposition and autoimmune mechanisms. The epidemiology of MS (see below) suggests that environmental factors may trigger MS.

2.2.1 Genetic predisposition

The involvement of a genetic factor in the pathogenesis of MS is suggested by the following lines of evidence:

Twin studies. Twin studies showing greater concordance of MS in monozygotic than dizygotic twins suggest that inheritance is important for MS susceptibility (Ebers et al., 1986).

Human Leucocyte Antigen (HLA) and MS. Population studies have found a relationship between the class II alleles DR 15 and DQ6 and MS susceptibility (Olerup et al., 1989).

Genetic background. Although there is evidence showing that MS occurs in all three of the main racial groups in the world (white, oriental and black), regardless of the country in which they are living, the highest incidence has been reported in areas of the world with a majority white population (McAlpine, 1991). Orientals, Eskimos and North American Indians have low rates of MS (Detels et al., 1977).

Genome Screening. Studies of the entire genome of patients with familial MS indicate that a number of genes may be involved in MS susceptibility (Compston 1997).

2.2.2 Autoimmune mechanisms

It is postulated that the immune system has a dormant pool of autoreactive T cells including cells that can cause inflammation or demyelination of the CNS. These become activated when triggered by an unknown factor. Activated T cells may then cross the blood brain barrier and be stimulated by exposure to an antigen in the CNS. Inflammation results and damage to the myelin and oligodendrocytes occurs (Pender 1995). There is increasing evidence that MS

is an autoimmune disease with pathological features of MS being reproduced in laboratory animals by immunisation with myelin antigens. This immunisation induces a disease known as experimental autoimmune encephalomyelitis (EAE). EAE is used to investigate disease processes relevant to MS (Pender 1996).

2.3 Epidemiology of MS

2.3.1 World wide incidence and prevalence

It is estimated that there are 2,500,000 people with MS in the world (International Federation of MS Societies 1998). MS is common in Northern Europe, North America and Australia but rare in the Orient, Asia, the Indian subcontinent, Africa and South America. Compston (1997) documents the epidemiology of MS. Prevalence of MS in Europe varies from 280/100,000 in Scotland; 100/100,000 in southern England; 105/100,000 in Denmark; 110/100,000 in Switzerland; 35/100,000 in Italy; in North America prevalence ranges from 65/100,000 in the west coast; 110/100,000 in the midwest and 70/100,000 on the east coast of the United States; 120/100,000 in British Columbia, Canada. It has been suggested that the distribution of the disease, varying with latitude (more distant from the equator the higher the prevalence of MS), reflects the involvement of an environmental factor in the aetiology (Limberg, 1950).

Several clusters of cases of MS have been reported which also suggest a viral/bacterial aetiology for MS. The best known of these was in the Faroe Islands: MS was almost unknown there before World War II; however, after occupation by British troops many cases were reported, and the prevalence is now one of the highest in the world, 300/100,000 population (Kurtzke et al., 1995). A cluster of cases related to a zinc factory in Rochester NY (Stein et al., 1987) suggested that other environmental factors may also play a role in triggering MS. Exacerbations of MS have been related to upper respiratory tract infections (URTI) (there is a threefold higher incidence of exacerbations in patients with URTI) (Sibley et al., 1985). Exacerbations of MS can be triggered by stressful life events (Franklin et al.,1988). It has been shown that MS prevalence is increased in higher socioeconomic groups, in which smaller families, larger houses and better personal and family hygiene tend to postpone infection until later ages (Waksman, 1989).

2.3.2 Multiple Sclerosis in Australia and Queensland

MS affects over 10,000 Australians. The exact number of people with MS in Queensland at present is not known, however an exhaustive study by Hammond was carried out in 1987 when the Queensland population was 2,295,122. There were 420 documented cases of definite and probable MS, in the whole of Queensland giving a prevalence of 18/100,000. South of the Tropic of Capricorn, 356 cases were identified, a prevalence of 20.9/100,000, compared with a prevalence of 11.8 above the Tropic of Capricorn (Hammond

et al 1987). It is interesting to note that MS is a rare disease amongst the Aboriginal and Torres Strait Islander populations, with no cases being documented in Hammond's study nor any previous studies (Hammond et al 1987).

The increasing prevalence with increasing south latitude was confirmed by McLeod et al (1994), for example, in Tasmania, MS has a prevalence of 75/100,000, a three fold increase when contrasted with Queensland 18/100,000 (Hammond et al 1987).

Historically, Queensland has had a high population migration rate from the people of United Kingdom and Ireland, both known high risk groups. It has been shown that if people migrate before the age of 15 they take on the risk of the new geographical location, however, if migration occurs after the age of 15 years of age, the high risk status is maintained (Dean and Kurtzke 1971: Detels et al 1978). This suggests that there may be some event occurring prior to the age of 15 which has an impact of the development of MS in an individual.

2.4 Diagnosis of MS

Diagnosis is made by detailed clinical history and physical examination, usually by a specialist neurologist. The diagnosis is based on the clinical examination as well as other investigations including magnetic resonance imaging (MRI),

examination of the cerebrospinal fluid (by performing a lumbar puncture) and visual evoked responses (Pender, 1996).

The diagnosis of relapsing remitting MS requires evidence of two separate attacks involving different parts of the CNS occurring over a period of months. Primary progressive MS is more difficult to diagnose and, like relapsing remitting MS, there is a time element involved documenting the progressive neurological deterioration with clinical, MRI or neuropsychological evidence of new lesions in the CNS (Pender 1996). Secondary progressive MS occurs when a person with RR MS does not recover from the last attack and consequently experiences a worsening of the disease without subsequent remissions.

2.5 Drug Therapies for multiple sclerosis

There are a number of drugs used to treat MS, but no known cure. The therapy of MS can be divided into treatment of the disease process and treating the symptoms.

Therapy for the disease process can be further divided into treatments given to speed recovery from an acute attack and treatments intended to reduce the rate and severity of future attacks. High dose methyl prednisolone is given intravenously to patients with a moderate to severe attack of MS to hasten recovery. This is administered in daily infusions over a five day period. Mild

attacks are not always treated as these do not severely limit the daily life activities of the patient. Intravenous methylprednisolone is also used for patients who have chronic progressive disease which may respond when the disease is worsening at a rapid rate (Pender, 1996).

Prevention of further deterioration is a major concern for people with MS and, in 1996, a beta interferon therapy was made available. The annual cost for treatment of one patient with beta interferon is $A14,000, subsidised in Australia by the Commonwealth Government. This drug, self injected every second day, has been shown to reduce the severity and number of attacks for people with relapsing remitting MS (The IFBN Multiple Sclerosis Study Group, 1993). The same study has also shown some benefit in reduction of brain lesions seen on magnetic resonance imaging (MRI) after treatment for two years. Other therapies which are used with some limited success include immunosuppressants, plasmapheresis and intravenous gammaglobulin.

Symptomatic treatments are important as problems such as spasticity, neuralgic pain, paroxysmal symptoms, fatigue, urinary problems and impotence require specialised assessment and appropriate treatment regimes. Symptoms may be reduced in severity but often the patient is left with symptoms which are mild to moderate.

2.6 Use of Health Services by people with MS

2.6.1 Mainstream Medicine

The demand for health services by people with MS varies with individuals, the levels of the disability experienced and the individual differences of emotional and personal needs. (Hainsworth 1994). Chronic diseases have both physical and mental components and are permanent features of the person's life. For people with MS there is an ongoing dependency on physicians, other health practitioners, therapeutic regimes and surgical procedures (Verbrugge and Patrick 1995) .

A study by Black et al. (1994) provided an extensive demographic profile of the social and service needs of people with MS living in New South Wales. In Black's study, 40% of the people with MS were managing personal needs themselves, with 50% requiring either their partner's help or a family member. Only ten percent were using health professionals for daily care and activities of daily living. Physiotherapists, urologists, social workers, occupational therapists, community nurses and psychologists were all listed by patients as health professionals significantly involved in the ongoing care and management of MS. The patients in this study identified a lack of knowledge of MS of health professionals as a barrier to the delivery of appropriate health care to patients with MS.

2.6.1.1 Professional Health Service Providers

Family physicians (general practitioners) are primary health care providers and are strategic in the delivery of holistic health care. The role of general practitioners is diverse, providing and coordinating health care for individuals with complex needs. In Australia, the family physician is seen as the primary health professional that people in the community approach for health information, direction and support for their health needs.

Patients with MS in New South Wales were asked to rate the most important health professional in the ongoing management of their MS (Black et al 1994). The family physician was listed as the most important health provider, with neurologists and other allied health workers ranked in decreasing importance. This primary care approach has a dual role in enabling and prioritizing the wide variety of patients' needs and providing an avenue for developing the patient-doctor relationship during the ongoing health care process (Stange 1998). People with MS, particularly those with progressive disease, require a family physician committed to providing a link between health services and resources of the health care system. In Australia, the family physician (general practitioner) is generally the primary health care provider.

Neurologist. In the USA, Enteen (1995) surveyed 358 patients with MS. In this study 56% of patients identified their neurologist as the primary care physician, while 32% viewed the general practitioner as primary care provider. This is in contrast with Australia, where the health system requires that a patient has a referral from his or her general practitioner to specialist doctor. The neurologist is the relevant medical specialist consultant for people with MS.

Allied health professionals, occupational therapists, speech pathologists and physiotherapists have a major role in the care of the disabled person. DiFabio et al. (1998) studied 46 MS sufferers with progressive disease, half of whom were given rehabilitation treatment programmes for one year, involving weekly outpatient visits and supervised rehabilitation sessions, while an untreated placebo group were put on a 'waiting list' for one year. They concluded that outpatient rehabilitation programmes for persons with MS, in particular those with progressive forms of MS, had an important role in the management of symptoms of fatigue and physical well being. They also showed that through this rehabilitation programme there was preservation of physical and cognitive functioning and also the facilitation of interaction within existing family networks. Patients on this programme had significantly fewer symptoms and also an improved quality of life.

Multiple sclerosis specialty clinics also have a role to play for people with MS and these clinics can support the central role of the GP in delivery of

appropriate and accessible health care. The specialty clinic provides expert opinion in the continuing management of people with MS and can be involved in the treatment of exacerbations and complications of the disease process. Specialty clinics are common place in the United States and there is a trend in Australia to provide such clinics. One MS specialty clinic in Queensland is located at the Royal Brisbane Hospital and in other Australian states and territories, outpatient clinics are held in major city hospitals.

2.6.1.2 Support Services

Support services for people with MS are diverse. Support groups find their impetus from within the local community of people with MS and their carers. Self help groups have been established in both city and rural communities and are self managed.

Multiple Sclerosis Society of Queensland (MSSQ)

The MSSQ provides assistance for the people with MS in Queensland. People registered with the MSSQ are able to access services at no cost ($10 yearly registration fee). The list of services provided is shown in Table 2.3.

2.6.2 Complementary Therapies

2.6.2.1 Definition

There is no strict definition of complementary therapy. Complementary therapies cover a diverse range of practices and can generally be described as non proven therapies and practices that have not been scientifically documented as safe and effective. For the purpose of this thesis complementary therapy will be defined as those therapies not prescribed by recognized medical practitioners. A practice such as counselling, which may be a component of mainstream management of MS, would thus be classed as complementary if it was prescribed by an alternative therapy practitioner. These therapies may be used concurrently with prescribed medications or as an alternative therapy.

They arise from different traditions and historical backgrounds, and include acupuncture, guided imagery, chiropractic, yoga, hypnosis, biofeedback, aromatherapy, homeopathy, relaxation techniques, reflexology, traditional chinese medicine, macrobiotics, iridology, and various schools of massage. Wanning (page 349, 1993) describes the use of complementary therapies as "viewing the body and mind as a balanced whole" which through techniques such as massage, acupuncture, t'ai chi and feldenkrais facilitate healing through relaxation, pressure points and movement. Different complementary therapies may have different theoretical and philosophical bases.

Table 2.3 Services provided by the MS Society of Queensland (MSSQ)

- accommodation and respite care for the person with MS
- physiotherapy - initial assessment and treatment plan for individuals and a referral system to a local public hospital physiotherapy department or private therapist
- counsellors for individuals and their families and advice and support with employment issues.
- allied health support and assessment including occupational therapy, speech pathologist and psychological support
- programme co-ordinators and case management for the MS sufferer and the family unit
- financial assistance and ways to access loans
- children's support programmes and support groups for people with MS
- outreach to country areas for patients, health professionals and community workers
- advice on transport and services available in the community
- support to access recreational and leisure activities
- community education and training of volunteers
- advice and hire of equipment and aids for activities of daily living and home comfort

2.6.2.2 Use of Complementary Therapies

There is a world wide trend, reported by European, North American and Australian investigators, for increased use of complementary therapies by populations who are suffering illness and also by those who are well. (Maddocks, 1985, Fulder and Munro, 1985, Clinical Oncology Group, 1987).

United States

Eisenberg et al., (1993) surveyed 1539 healthy American adults to find the prevalence of use of unconventional therapies. They found that one in three adults reported using at least one unconventional therapy in the past year, one third of these visiting alternative therapists. The vast majority (85%) of those with a serious illness, also sought treatment for the same condition from a medical doctor. Paramore (1997), analysing data from 3450 normal subjects, showed that nearly 10% of the 'well' US population saw an alternative therapist.

Anderson et al (1993) recruited 184 HIV positive patients, from three HIV clinics in the Philadelphia area, into a study which investigated the extent of recourse to alternative therapies while attending mainstream medical clinics for disease management. Forty two percent of subjects reported using complementary therapies.

Studies into other chronic, debilitating incurable diseases have shown that the use of complementary therapies is widely practiced. Cronan (1989) in San

Diego, in a study of musculoskeletal diseases, found that as many as 90% of people with these disorders used complementary therapies. Donnelly et al (1985) demonstrated that 45% of people suffering from asthma had consulted alternative practitioners at some time, most popularly chiropractors and homeopaths.

A centre for evaluating alternative medicine in the treatment of HIV/AIDS was established in October 1994 in Seattle, Washington. This centre is currently evaluating therapies for HIV/AIDS in conjunction with a network of alternative therapy clinics in the United States. The aim is to determine whether patients who use both alternative therapies and conventional medicine have different outcomes from patients who only use conventional therapies (Standish et al 1997).

Canada

Millar (1997) estimated that 15% of Canadians, surveyed in 1994-95, used some form of alternative therapy. Among persons free of chronic illness, Millar found that 9% consulted alternative therapist compared with over 26% of those suffering a chronic disease.

Singh et al., (1996), in a study of the use of nontraditional therapy by people with HIV infection, documented that 30% of the subjects used such therapies. Singh et al showed that recourse to non-traditional therapies was common

amongst people who are HIV infected, not because they are depressed or emotionally disturbed, but because they seek greater control of the outcome of their disease. There was, however, no beneficial effect of the disease progression when compared with patients receiving only conventional medical therapy (Singh et al 1996).

Netherlands

Another study of HIV patients, in the Netherlands, demonstrated that over 30% of patients were using alternative therapies (Wolffers and deMoree1994).

Norway

Of 642 respondents to a Norwegian study of cancer patients, 20% had been or were users of alternative therapies for their oncological disease (Risberg et al 1995). Risberg et al., documented the incidence of nonproven therapy use amongst cancer patients as 45% in a five year prospective study, which also showed that women were more frequent users of complementary therapies than men (50% vs 31%, P=.002). Risberg et al. showed that non proven therapies did not influence survival amongst cancer patients in north Norway and also showed a trend that complementary therapies are most often used by people from a higher socioeconomic background and with higher education (P=0.06) (Risberg et al., 1998).

Thus, it is not unusual for people with chronic diseases, nor in fact for the

general population, to use complementary therapies.

Australia

In Australia, MacLennan et al (1996) surveyed 3004 persons aged 15 and older living in South Australia. Forty-eight percent of those interviewed had used at least one complementary therapy in the last year, while 20.3% of all survey participants had visited at least one alternative practitioner.

Lloyd (1993) studied a population of 289 Australians with an extensive array of ailments, for whom allopathic medicine had been unsuccessful. All the subjects resided in Sydney. Almost half (41%) the sample population had attended an alternative therapist for over a year, while another 11% had commenced complementary therapy within six months prior to the survey. These therapies were not reimbursed by Medicare.

A major public hospital in metropolitan Sydney assessed the patterns of alternative medicine used in its public hospital oncology unit which showed a 21.9% use of alternative therapies (Begbie et al., 1996). The investigators concluded that a significant number of cancer patients were using one or more alternative therapies, and proposed that this usage may reflect deficiencies in the standard of care given.

The Australian Federal Government has recently implemented several

initiatives in the area of scientific standard for complementary therapies. The CMEC (Complementary Medicines Evaluation Committee) in parallel to the ADEC (Australian Drug Evaluation Committee) meets on a regular basis to consider new items on the market and reconsiders old items if there are current safety issues. The ADRAC (Adverse Drug Reactions Committee) considers all reported drug reactions in Australia and has for the last two years included reactions from complementary medicines.

2.6.2.3 Reasons for using complementary therapies.

The reason why people use complementary therapies is multifactoral. Donnelly et al., (1985) identified well individuals and individuals with used both complementary therapies and orthodox medicine. Donnelly et al. concluded that there was no support for the view that users of alternative therapies were disgruntled with orthodox medicine.

As previously mentioned, patients infected with human immunodeficiency virus (HIV) are turning to non traditional therapy (Singh, 1996) which, although there is no proven impact on the long term outcome of the disease, gives greater control to the patient in process of managing their disease. Astin (1998) studied 1035 randomly selected well individuals from the United States, who had agreed to participate in mail surveys, and found that they did not use alternative therapy because they were dissatisfied with conventional medicine

but as an adjunct. Alternative therapies were found to be more congruent with their own values, beliefs and philosophical orientations toward health and life.

Fawcett et al. (1994) demonstrated that, while 100 percent of MS sufferers in the study population living in New England area of USA, continued under the primary care of a physician, 63% were concurrently visiting an alternative health practitioner. Anecdotal evidence has suggested that there is concurrent use of both complementary therapies and mainstream treatments within health care services by people with MS.

2.6.2.4 Issues associated with using complementary therapies

Increased use of complementary therapies has caused some concern amongst mainstream conventional medical practitioners.

There is a potential harm to the consumer of these complementary treatments. A small study in Ireland discussed the impact of alternative medicine on renal function (Farrell et al., 1995). Physicians observed three nephrotoxic individuals who suffered irreversible renal impairment due to ingestion of complementary therapies.

Patients may abandon appropriate proven therapy to pursue potentially harmful alternative therapies and McGinnis (1991) has called for public and professional education to discuss the role and dangers involved in the use of

complementary therapies. Brigden (1995) pointed out that physicians need to discuss with their patients any questionable therapies that may be in vogue in their geographical and medical specialty areas. LaValley and Verhoef (1995) suggested that documentation of patient use of complementary therapies should become a part of the complete patient medical history. This may promote greater patient-physician communication and consequently enhance the quality of care.

Exploitation of patients by unscrupulous therapists is possible and McKnight and Scott (1996) pointed out that doctors who are aware and educated about their patients' use of non proven therapies would be in a better position to defend and advise their patients against exploitation or unsafe treatment. Anderson et al (1993) stated that medical practitioners and other health care workers need to be aware of their patients' interests and priorities and work with them in decision making about their treatment regimes in order to achieve satisfactory outcomes.

Another important issue of complementary therapy use is the paucity of safety and efficacy data. This raises major concerns for public health. Another concern is that use of complementary therapy may incur large costs by individuals. There is also the possibility that a person using an alternative therapy could delay consultation with a physician who may have therapy that will benefit the patient. Freeman et al (1997) sees the challenge for health care

providers as responding appropriately to the notable prevalence of alternative health practices and the complex societal factors that nurture their usage.

2.7 Impact and economic cost of multiple sclerosis

2.7.1 Quality of Life

Quality of life for people with MS deteriorates early in the disease process and worsens as further disability and physical functioning becomes affected. It has been estimated that 85% of people with MS are disabled to some degree because of their MS (Canadian Burden of Illness Study Group 1998). Disablement may mean restrictions in opportunities for employment, limiting activities of daily living activities and also difficulties in relating to others (McLennan et al., 1996).

MS can impose limitations in all areas of life. Multiple sclerosis, as previously stated, is usually progressive in nature, often leading to physical and sometimes mental deterioration (Confavreaux et al., 1980, Weinshenker, 1989). The uncertainty of the disease course and the disabling affects of the disease have profound impact on the lives of individuals, family members and carers. For the individual, impairment of physical, cognitive and emotional faculties can result in strained relationships within the family situation, socially and in the work place.

The need for help, the risk of divorce, loss of contact with relatives, difficulty with going out and the need for changing house structures to accommodate the worsening physical handicap place people with MS under a great social and economic strain (Stenager et al., 1994). Some people diagnosed with MS withdraw from intimate relationships or choose not to inform their families or friends of their MS.

Physically disabling symptoms experienced by people with MS have a significant impact on their ability to maintain daily life activities. Unsteady gait and balance disturbances may cause fear of mobility and frequent falls. Loss of co-ordination can result in apparent 'clumsiness' and difficulty in carrying out routine self care activities. Simple message writing or buttoning clothes can become difficult tasks, and on days when the person is experiencing a worsening of their disease, these simple tasks become impossible to accomplish (Rudick 1990). Coping with such stresses in the individual's personal life requires a network of supportive people and resources (Murray 1995).

Many people with MS suffer embarrassment because of loss of control of bladder and bowel function. This loss of control may cause urinary or faecal frequency, urgency or incontinence, sometimes in public places. Eye problems, such as blurring of vision, double vision and sometimes loss of vision may occur for days or weeks, making daily activities, car driving and mobility difficult

if not impossible. Pain and altered skin sensation along with unsteady gait and loss of proprioception make it difficult for the individual to be mobile. Sensory and motor disturbances can cause major impact on patients. A 1998 survey of 198 MS Canadian patients, showed that early in the MS disease process, using a Quality of Life generic assessment (SF- 36), there was a substantial reduction in the quality of life compared with the normal population. As the persons' disability worsened, so too did the quality of life (The Canadian Study Group 1998).

2.7.2 Economic cost of MS

The cost of health care for people multiple sclerosis is large, both to the individual and the community as a whole. The cost of MS in a number of western societies has been studied and is summarised below.

United States

There are an estimated 350,000 people with MS in the United States (Fawcett et al 1994). In the United States, in a study of 606 people with MS, the national annual cost of medical care, personal services, alteration to home, vehicles, purchase of special equipment and earnings loss was in the billions of dollars (Whetton-Goldstein et al 1996). Bourdette et al (1993), have shown that over half the total number of individuals with MS in the United States, became unemployed because of the disease within 10 years of their diagnosis. The average cost of MS, per person per year, was $US34,103 with the largest cost

being lost wages, averaging $17,900 per person annually. The breakdown of these costs included care giving by family members ($US6,452), home and person assistance by paid care givers ($US1,247), hospital costs ($US2,485), physicians costs ($US1,746), medications ($US $US847), nursing home care ($US845), retraining ($US944) and other costs ($US556). The investigators found that for people with the progressive form of MS, the costs were much higher, averaging $US49,084/person/year (Whetton-Goldstein et al 1998). The cost to the individual with MS varies according to individual needs and disease severity. Enteen (1995) states that one of four American MS families cannot meet basic living expenses with their current family income, and long term care is a major problem for most, as the majority are under-insured.

Canada

There are an estimated 35,000 people with MS in Canada (The Canadian Burden of Illness Study Group 1998). It was estimated that the total cost for all Canadians with MS in 1994 was $CDN502.3 million, which included both direct costs (hospital care, other institutions, physician services, other health professionals and drugs) and indirect costs (loss of productivity due to premature mortality and disability) (Asche et al 1995). The annual costs per patient were calculated from provincial data showing a range of $CDN14,523 to $CDN37,024 for patients with increasing mild to severe disability, defined using EDSS. In all these groups most of the financial burden is borne by the patients themselves (from 74% to 88%). The major costs to society were lost daily

activity and lost productivity. The life time cost of MS, including patient institutionalisation was estimated at $CDN1,608,000 per patient (Canadian Burden of Illness Group, 1998).

United Kingdom

There are approximately 85,000 people with MS in the UK (Hatch, 1996) In 1994, the total annual cost of multiple sclerosis to the state and National Health Service in the United Kingdom was 1.2 billion pounds. These figures are based on a questionnaire circulated to 999 people with MS in the UK. The major financial burden, 536 million pounds per year, is borne by the individuals and families affected by MS. The greatest economic loss is from lost earnings, but also includes cost of child care, housing alterations and purchase of special supplies and equipment. Hatch documents the cost to the State in financial benefits paid and lost tax revenue is 435 million pounds per year and the cost to industry in lost productivity amounts to over 40 million pounds per year. A significant economic burden is also borne by the family and non professional carers, who have to be absent from paid work in order to provide care for the person with MS (Holmes et al 1995, Hatch 1996).

Holmes et al (1995) points out that while the health care systems of the UK and USA are different, "disabling, long term illness imposes a significant economic hardship on families afflicted with illness and on members of the society as well" (1994 Inman). Indirect costs, such as lost daily activity and lost

productivity are a major economic burden to society (The Canadian Burden of Illness Group 1998). The costs need to be considered by health service delivery systems in order to set priorities for research and treatment activities. The cost is ultimately shared by individuals and society as a whole.

Australia

The cost to the health care system, for the estimated 10,000 people with MS in Australia, has not yet been documented. However, it would be likely to mirror that of the Canadian and UK experience where Hatch (1995) states that the economic burden of MS, to the individual and the state, is significant.

2.7.3 The economic cost of complementary therapies.

The cost of these complementary therapies is not included in health care costs as listed above.

The United States

Eisenberg et al., studied 1539 adults in North America (1993). They found that one in four Americans who see their medical doctors for a serious complaint were using non prescribed therapy in addition to mainstream prescribed medicine for that specific problem. Seven of ten of such occurrences took place without patients telling their medical doctors that they used unconventional therapy. Eisenberg et al also state that the number of visits in 1990 to providers of unconventional therapies was greater than the number of

visits to all primary care medical doctors nationwide. The amount of money spent out of pocket ($US10.3 billion) for unconventional therapies was comparable to the amount spent out of pocket by Americans for hospitalizations ($US12.8 billion), and just under half the amount spent for all physicians' services ($US23.5 billion) in 1990. Not only people with serious complaints were using complementary therapies. At least one in three individuals with back problems, anxiety, depression or chronic pain, were using nonconventional therapies without disclosing this to their physician. As Eisenberg et al state "unconventional medicine has an enormous presence in the US health care system" (1993).

Of 1,811 people living in metropolitan San Diego, United States, 382 reported having musculo-skeletal complaints. Eighty-four percent of the 382 subjects had used complementary therapies within the previous 6 months (Cronan et al 1989). Commonly used remedies included prayer (44%), non prescribed exercise (33%), relaxation (33%) and whirlpool/hot tub treatments (29%). Sixty-one per cent of people using hot tubs stated that they were very helpful, and prayer was rated by 54% of the users as being very helpful. Cronan et al found that the use of expensive unconventional therapies was uncommon. Their finding suggests that the use of unconventional therapies is widespread but the most popular therapies are neither harmful nor expensive. They state that the remedies may provide patients with a sense of control over their disease (Cronan et al., 1993).

The use and types of alternative therapies were assessed in 3004 people in a South Australian community by MacLennan et al. (1996). In the year 1992/93 extrapolation of the costs to the Australian population, gives an expenditure of $A621 million per annum for alternative medicines and $391 million per annum for consultation with alternative therapists. A total of $1 billion per year to the Australian population. When this is contrasted with the total amount spent in by all Australians on pharmaceutical drugs ($360 million per year), expenditure on complementary therapies is quite significant. These figures raise public health issues of safety and efficacy when use of complementary therapy is used by a large number of the total population (MacLennan et al., 1996).

Complementary therapy for people with MS, Fawcett et al. (1994), in a small American study of 16 people with MS, found that eight (50%) of the study participants, had spent more than $US1000 for alternative treatment in the past year. Thirty seven percent reported spending more than $US10,000 on alternative therapy since their MS symptoms began. Some of the complementary therapies used included touch therapy, acupuncture, naturopathy, homeopathy and herbal medicine. Forty four percent of people stated that the quality of their lives was improved by alternative therapies.

In Australia, there are no studies which specifically address the use of complementary therapies in multiple sclerosis.

2.7.4 Unmet Needs of Patients with MS

In a preliminary study of 358 people with MS, when asked for evaluations of their medical care, the most common complaint by respondents was "lack of caring" by health providers (28%), followed by "lack of knowledge about MS" (22%) and "failure to diagnose" (19%) (Enteen 1995).

It has been demonstrated that emotional needs of the person with MS are of major importance in managing ongoing care. According to Black (1994) the physical needs of the person are more often met than the emotional needs. Main areas of concern for the person with MS were loss of employment, fatigue, lack of respite care and need for extensive family support. People with MS felt that the lack of understanding about the disease by family members caused breakdowns of relationships in their family network. Approximately 30% of the patients stated that their needs were not met in areas of long and short term breaks from home and in receiving support from other people with MS.

Support networks, such as self help groups, and aids to allow independence in activities of daily living, were not being provided for people with severe physical disability. Williams and Bowie showed that, in patients with MS, there was a high prevalence of unmet needs to accomplish daily life activities as the physical disability worsened (1993).

This finding is not confined to MS. In HIV/AIDS patients, 20% of the patients identified lack of non institutional services, such as mental health support, as a

major area of unmet needs by health providers (Bonuck et al 1996). Patients with chronic diseases attending medical clinics in Portland, Oregon, stated that their desire for emotional support and information regarding their disease were the two most frequently unmet needs (Joos et al 1993). Patient satisfaction with medical care received was seen to be compromised and this jeopardised health outcomes. A similar finding was described by Allen and Mor, (1997) when patients with a physical disability in Rhode Island, USA, were investigated to determine the prevalence and consequences of unmet needs. Inadequate help in daily activity areas such as eating, transferring (moving from bed to chair or toilet), cooking, heavy housekeeping and transportation, impeded the management of chronic health conditions and compromised the individual's ability to maintain a safe and reasonable quality of community living.

2.8 Rationale for the Present Study

Documentation of the use and cost of both mainstream and complementary therapies is required in order to understand the needs of people with multiple sclerosis (MS). Documentation of the extent of use and cost of complementary therapies serves as part of the holistic approach to health care. The present study of complementary therapies arose from personal observation by the investigator who had had close regular contact with many people with MS over a three year period. It became evident that there was a heavy use of complementary therapies by people with MS and that for some people this involved considerable financial outlay. It was also apparent that the taking of

these medications caused anxiety for individuals who were seeking approval and direction in the area of complementary therapies.

2.9 Aims and Objectives of the Present Study

The aim of the present study was to document the services accessed by people with MS, and to identify what mainstream medicines and complementary therapies were used, how frequently and at what cost. This is the first such study in Australia.

The study used a questionnaire to interview subjects concerning the use of mainstream medical services and complementary therapies. It was not within the scope of this study to determine effectiveness of complementary therapies.

2.10 Hypotheses

The study examines four main hypotheses.

1. That people with MS access a range of mainstream services according to their needs
2. That many people with MS use complementary therapies.
3. That there is a wide range in the cost of complementary therapy to individuals
4. That people with MS are using complementary therapy as an adjunct therapy with mainstream therapies in managing their MS

Chapter 3 Methodology

3.1 Introduction

People with multiple sclerosis live with the uncertainty of a disease which cannot be cured and a disease process which is usually progressive in nature. Documentation of the use and cost of both mainstream and complementary therapies was required in order to understand the needs of people with multiple sclerosis. The data were obtained by interview and administration of a questionnaire developed by the investigator who had close regular contact with many people with MS over a three year period. The emphasis on complementary therapy emerged as it became evident that there was a heavy use of complementary therapies by people with MS in this group and that for some people this involved considerable financial outlay. The use of complementary therapies was a common theme in many conversations with people with MS.

3.2 Development of the Questionnaire

3.2.1 Preliminary

The questionnaire was based on other questionnaires used by the investigator in previous multiple sclerosis research projects and specific questions raised by people with MS about complementary therapies. The questionnaire was designed to document the cost and use of mainstream and complementary therapies. Core information on demographic and MS disease information was

included in order to classify individuals by MS types, duration and severity of disease.

3.2.2 Focus group

A preliminary questionnaire was produced to detail demographic, mainstream health services and complementary therapies used and the cost of these to the consumer. The investigator read through the questions to the focus group of three MS patients. The investigator had a prepared questionnaire for discussion and as comments were made by the focus group participants, the investigator scribed, collated and incorporated these into the final draft of the questionnaire.

From discussions with these individuals it was decided that the best approach was a face to face interview, in the patient's home when possible, with the interviewer recording the responses. This was suggested because patients have problems with fatigue, transport difficulties and mobility. It was also suggested that some questions be 'open ended' to allow for comments about health services, complementary medicine and other issues that are of concern to the person with MS. This part of the interview became the source of the list of 'unmet needs' of patients with MS.

3.2.3 Questionnaire

The questionnaire consisted of 5 pages (Appendix A). Ethics approval was given by Royal Brisbane Hospital ethics committee and a signed consent by the participant was obtained. An information sheet was provided, indicating the study objectives, patient privacy procedures and the interview process.

The questionnaire consisted of four sections.

a) demographics

b) the frequency of mainstream health services accessed and the cost involved

c) the frequency and cost of complementary therapies used

d) health care services - open ended questions allowing for documentation of services areas of major concern.

3.3 Study Population

3.3.1 Criteria for participation in the study

- A diagnosis of definite MS from medical records
- To give consent for a personal interview.
- To have adequate English speaking skills
- Newly diagnosed MS patients were excluded

3.3.2 Number of study subjects

Everyone who attended the hospital for an appointment or who was phoning for another reason, was approached to participate in the study. Some people were

also participating in other MS research projects carried out in the hospital. All forty people that were approached agreed to be participants in the study. All the interviews were carried out over a 6 month period.

3.3.3 Interview Process

Once the patient had consented to participation, the time and place of the interview was scheduled. The majority of the patients lived within four hours car journey from Brisbane and interviews were carried out at home. On four occasions the interview was carried out in the hospital clinic.

Fatigue. An important consideration in this study was that people with MS are easily fatigued. This is a well documented feature of the disease. As involvement in the study would require commitment to an interview and a questionnaire, extra effort was required from the patient and it was envisaged that the interview process would cause fatigue. To accommodate patients, consideration was given to the time of day that the interview was carried out. The majority of interviews were scheduled in the morning, when the patient is less fatigued.

Personal needs. Many patients required attention for personal needs and also assistance with routine morning schedules. Carers, for the more disabled, needed time to manage and support the patient's personal needs prior to the arrival of the interviewer. Due consideration was given to arrange this interview

so that neither the patient nor the carer felt undue pressure prior to or during the interview process.

Extent of disability. Another factor dictating the interview process was the nature and extent of the patient's disability. Some subjects experienced significant weakness, incoordination of the hands and consequently could not sign consent forms. Verbal consent to participate in the study was given by these people, witnessed by their family member or carer. Other patients had impaired vision (either loss of vision or blurred vision) and consent forms and explanations of the project needed to be read.

Cognitive impairment. Some patients were not able to concentrate for an extended period of time and therefore small breaks were included between questions. The interviewer therefore documented all interviews herself, as attention span and physical exertion waxes and wanes for the patient with MS.

Transportation. Travelling to the person's home, or a mutually convenient place was negotiated on a person to person basis. Transportation can cause significant logistic difficulties and physical limitations for the person with MS. This factor, along with the effort required for the patient in walking with the use of sticks and mobility frames, meant that where possible, interviews were held at the person's home. The interview, which lasted approximately one and half

hours was most suitable in the home situation as it provided the best environment to carry out the interview.

The study population represented people who were able to speak about their disease and who already had contact with the health system. Some people with mild MS are able to manage small disease fluctuations without seeking the help and support of medical services, and would not have been part of the group targetted for this study.

3.4 Data Collection and Analysis

Table 3.1 Interview Data

- age, sex, employment status
- educational qualifications
- disease types
- duration of disease
- disability profile (EDSS) - Kurtzke's rating of neurological impairment
- mainstream health services used
- complementary therapies used
- cost of mainstream therapies
- cost of complementary therapies
- patient satisfaction with complementary therapies
- unmet needs / general comments

The data collected were stored using Excel and Microsoft Access. All completed questionnaires were entered into an Excel Database and analysed.

Chapter 4 Results

4.1 Demographics

Forty people were approached and all agreed to participate in the study. All the study subjects were diagnosed with definite MS. There were no newly diagnosed subjects.

4.1.1 Age and gender

Table 4.1 shows the age and gender of patients included in this study. The study subjects ranged in age from 27 to 68 years, with the majority of patients (70%) between 40 to 59 years of age and only 13% greater than 60. The mean age was 49 years.

Table 4.1 Age and Gender of MS Patients

Age Distribution	Number	%
Total	**40**	***100***
20 - 39	7	*17.5*
40 - 49	11	*27.5*
50 - 59	17	*42.5*
60 and older	5	*12.5*
Sex		
Male	11	*28.0*
Female	29	*72.0*

The data were compared with the only previous study on MS in Queensland (Hammond 1987). There was a statistically significant difference between the age of the two populations, with Hammond et al. having a younger population (mean age 33 years) (Chi square p=0.02). Of the 40 patients, 28 (70%) were between 40 - 59 years old, 22 (55%) were older than 50 years and only 7 were

under the age of 39 (17.5%). As all newly diagnosed patients were excluded, the study population were further into their disease course and more likely to be older.

The ratio of 29 females (72%) to 11 males (28%) is consistent with Hammond (70.1% females and 29.9% males) and reflects the known ratio of prevalence of MS in females and males of approximately 2:1 (Pender 1996).

4.1.2 Employment and Educational Qualifications

Table 4.2 shows the employment status of patients in the present study. Just over one third (35%) of those in the study had either part time or full time employment while 26 of the 40 subjects (65%) were on a pension, (with only 5 of these being sixty years or older).

Table 4.2 Employment and Educational Qualifications

Employment Status	**# 40**	*%*
Employed	14	*35*
Pensioner	26	*65*
Educational Qualifications		
Secondary School	33	*82.5*
Tertiary Studies	7	*17.5*

Those with employment were in clerical, engineering or teaching professions. Tertiary qualifications were held by 17.5% (7) subjects.

4.1.3 Disease Category and Duration of the Disease

Table 4.3 shows the categories of disease and duration of disease of patients in the present study. Of the forty subjects, 18 (45%) had relapsing remitting MS; 12 people (30%) had secondary progressive MS and 10 (25%) primary progressive MS.

Table 4.3 Disease Categories and Duration of Disease

Disease Category	Number	%
Total	**40**	***100***
Relapsing Remitting	18	*45*
Secondary Progressive	12	*30*
Primary Progressive	10	*25*
Duration of Disease (yrs)		
<5	8	*20.0*
5-10	13	*32.5*
>10	19	*47.5*

The majority of patients had been diagnosed more than 5 years previously. Seventy five percent (18/40) of the people with MS had begun the disease course as relapsing remitting MS (RR) with 30% (12/40) having progressed to secondary progressive disease (SP) by the time of the study.

4.1.4 Disability measured by EDSS

Table 4.4 shows the disability status of patients in the study. The Expanded Disability Status Score (EDSS) demonstrates a wide range of independence / disability in the study population.

The majority (75%) of patients are ambulatory with EDSS 1-7, (35% needing some support or aids and 40% are fully ambulatory). The remaining ten people (25%) had severe disability (EDSS > 7.5) essentially restricting them to wheelchair mobility.

Table 4.4 The disability status of patients in the study

EDDS - (Expanded Disability Status Scale)		
	Number	**%**
1 - 5.5 Fully ambulatory without aid	16	*40*
6 - 7 Ambulatory with assistance or aid	14	*35*
7.5 - 9 Restricted to wheelchair	10	*25*

One patient, was completely dependent on her partner for all daily activities. This patient was able to swallow thickened fluids with difficulty, use her eye lids for communication and had very limited head and eye movement.

4.1.5 EDSS and Duration of Disease by Disease Categories

Table 4.5 shows the disability status, according to disease category and disease duration. Within individuals, it is expected that the disease course will worsen the disability of SP patients. Six of the ten people with an EDSS greater than 7.0 fell into the secondary progressive group. These people had a disability which basically restricted them to a wheelchair, often motorised (EDSS category of 7.5) There were 16 people (11 of whom had relapsing

remitting MS) with an EDSS score of less than 5.5. This indicated that for this group the disability was severe enough to impair full day activities. Individuals in this category may not, however, be able to work a full day without special provisions.

Table 4.5 EDSS and Duration of Disease by disease Categories

	Relapsing Remitting		Secondary Progressive		Primary Progressive	
	Number	%	Number	%	Number	%
EDSS Disability Score						
1 - 5.5	11	*61*	1	*8*	4	*40*
6 - 7	5	*28*	5	*42*	4	*40*
7.5 - 9	2	*11*	6	*50*	2	*20*
Total	**18**	***100***	**12**	***100***	**10**	***100***
Duration of Disease (years)						
< 5 years	2	*11*	1	*8*	5	*50*
5 - 10 years	6	*33*	4	*33*	3	*30*
> 10 years	10	*56*	7	*58*	2	*20*
Total	**18**	***100***	**12**	***100***	**10**	***100***

Of those with relapsing remitting MS only 2 individuals had an EDSS greater than 7, while 50% of those with secondary progressive MS (6/12) had an EDSS greater than 7. This shows the subjects in this study had an increasing severity of the disease with progression to the secondary progressive stage of MS.

Of the 18 patients with RR MS, 44% (8 subjects) had MS for less than 10 years, while 56% (10 subjects) had MS for over ten years, with two individuals having had MS for over 25 years. The primary progressive group had 80% (8

subjects) with a disease duration of less than 10 years. By definition, the people with SP MS had previously been classified with RR MS and had progressed to a secondary progressive disease course. Fifty-eight percent of SP MS had a disease duration of over 10 years.

Table 4.6 Categories of MS by Age and Sex (RR, SP, PP)

	Relapsing Remitting		Secondary Progressive		Primary Progressive	
	Number	*%*	*Number*	*%*	*Number*	*%*
Age						
20 - 39	4	*22*	3	*25*	-	*0*
40 - 49	7	*39*	2	*17*	2	*20*
50 - 59	6	*33*	5	*41*	6	*60*
60 & older	1	*6*	2	*17*	2	*20*
Total	**18**	***100***	**12**	***100***	**10**	***100***
Sex						
Male	4	*22*	3	*25*	4	*40*
Female	14	*78*	9	*75*	6	*60*
Total	**18**	***100***	**12**	***100***	**10**	***100***

Table 4.6 shows the categories of MS by age and gender. Patients with PP MS were more likely to be older and the percentage of males was highest in the group with PP MS (40%).

4.2 Use of Mainstream Health Services

Table 4.7 shows the use of mainstream health services by patients in the study. Because of the way in which they were recruited, all of the study participants were attending specialist neurological services, 38 of 40 subjects (95%) regularly (yearly), and 2 of 40 subjects (5%) sometimes (second yearly or when

a relapse occured.) All patients also had regular contact with their general practitioner who bulk billed.

Table 4.7 Use of Mainstream Health Services

Use of Mainstream Services	Regularly		Sometimes		Never	
	Number	*%*	**Number**	*%*	**Number**	*%*
GP	38	*95*	2	*5*	0	*0*
Specialist	38	*95*	2	*5*	0	*0*
Physiotherapist	21	*52.5*	2	*5*	17	*42.5*
MS Society	19	*47.5*	13	*32.5*	8	*20*
Community Health	13	*32.5*	2	*5*	25	*65.5*

Twenty one of forty subjects (52.5%) had regular or infrequent physiotherapy appointments. Eighty percent of subjects used the Multiple Sclerosis Society of Queensland (MSSQ), 19 of 40 regularly (47.5%), 13 of 40 sometimes (32.5%). Fifteen patients used community based services, (either community nurses or home attendant services).

There was no cost to the patient in attending the neurologist and general practitioner. The cost was covered by Medicare. For some employed patients, this was through Medicare levy of income. Community health services were also at no cost to the individual.

4.2.1 Influence of Age and Gender on mainstream services

Table 4.8 shows the use of mainstream health services by age and gender.

Table 4.8 Use of Mainstream Services by Age and Gender

	Number	MSSQ		Physio		Comm Health	
	40	n	%	n	%	n	%
Age (yrs)							
20-39	7	6	(85.7)	3	(42.9)	3	(42.9)
40-49	11	8	(72.2)	7	(63.6)	4	(36.4)
50-59	17	13	(76.5)	10	(58.8)	6	(35.3)
60>	5	5	(100)	3	(60.0)	2	(40.0)
Sex							
Male	11	10	(90.1)	7	(63.6)	3	(27.3)
Female	29	22	(75.9)	16	(55.2)	12	(41.4)

Note: all patients see a general practitioner and neurologist

Men were slightly more likely to use MSSQ (90% vs 75.9%) and physiotherapy (63.6% vs 55.2%). Whereas more women than men (41% vs 27%) accessed community health services.

Patients 60 years and older were highly likely to use MSSQ compared with those aged 40 - 49 and 50 - 59 (100% vs 72% vs 76.5%). Community health use was not impacted by age with 35.3% - 42.9% use across the 4 age groups. Physiotherapy was used less by 20 - 39 year age group, when compared with 40 - 49, 50 - 59 and >60 years old (42.9% vs 63.6%, 58.8%, 60%).

4.2.2 Influence of employment and educational level on the use of mainstream services

Table 4.9 shows the use of mainstream services by employment and educational qualifications. A greater number of the unemployed than employed accessed mainstream services, in particular, 14 of the 26 (54%) unemployed patients accessed community health services compared with only 1 of the 14 (7%) employed persons. This may suggest that those working were less disabled and were able to carry out activities of daily living, without requiring the assistance of community health nurses or attendants.

Table 4.9 Use of Mainstream Services by Employment and Educational Levels

	Number 40	MSSQ		Physio		Comm Health	
		n	%	n	%	n	%
Employment							
Yes	**14**	10	(71)	6	(43)	1	(7)
No	**26**	22	(85)	17	(65)	14	(54)
Education Qualification							
Secondary	**33**	26	(79)	19	(58)	14	(42)
Tertiary	**7**	6	(86)	4	(57)	1	(14)

Fourteen patients (42%) with non tertiary educational qualifications used community health services, compared with 1 of 7 (14%) persons with tertiary education. This may be explained by the fact that tertiary qualified people (5 of the 7 tertiary qualified people were employed) had access to employment that was not requiring as much physical ability to perform tasks in the work place.

The other mainstream services were used equally by both secondary and tertiary educated people with MS.

4.2.3 Influence of disease duration, disease category and EDSS on use of mainstream services

Table 4.10 shows the use of mainstream services by disease duration, disease category and disability (EDSS). Access to all services was increased as disability worsened. The MSSQ was used by 62.5% with a low EDSS (< 5.5) and 100% of the patients with a high EDSS (7.5 and greater).

Table 4.10 Use of Mainstream Services by Disease Duration, Disease Category and EDSS

	Number	MSSQ		Physio		Community Health	
EDSS		**n**	**%**	**n**	**%**	**n**	**%**
1-5.5	**16**	10	(62.5)	7	(43.75)	3	(18.7)
6-7	**14**	12	(85)	9	(64.5)	6	(42.8)
7.5-9	**10**	10	(100)	7	(70)	6	(60)
Disease Duration (yrs)							
< 5	**8**	5	(62.5)	4	(50)	3	(37.5)
5 - 10	**13**	10	(77)	6	(46)	5	(38.5)
> 10	**19**	17	(89.5)	13	(68.4)	7	(36.8)
Disease Category							
RR	**18**	13	(72)	10	(55.5)	6	(33.3)
SP	**12**	11	(91.5)	7	(58.3)	6	(50)
PP	**10**	8	(80)	6	(60)	3	(30)

As disease duration increased there was an increase in the use of MSSQ (62.5 % to 89.5%) except physiotherapy. (50% to 68.4%) but not community health.

People with SP MS were more likely to use MSSQ and community health services than people with RR MS and PP MS.

4.3 Complementary Therapy

Thirty three of 40 (82.5%) study subjects using complementary therapies. Table 4.11 shows the different complementary therapies used. Therapies have been grouped into non prescribed medications and physical/psychological therapies. See Appendix B for detailed description of some of these therapies.

Table 4.11 Complementary therapies used by study patients

Non prescribed medications	Physical /psychological therapies
• evening primrose oil	• counselling
• dietary manipulation	• polarity
• naturopathy	• kinesology
• vitamin supplements	• colour light therapy
• kambucha	• prayer and meditation
• shark extract	• massage
• bee venom	• feldenkrais
• picnogyl	• reiki
• marihuana	• lymphosizer
• aromatherapy	• bowen technique
• oxichel	• acupuncture

One subject used a combination of homoeopathy, vitamins (both oral and injected), acupuncture, naturopathy, touch for health, a powder additive to milk, kambucha tea, chiropractic techniques, aromatherapy, feldenkrais, therapeutic massage, herbal creams, colour light therapy and bowen technique.

4.3.1. The influence of age and gender on use of complementary therapies

Table 4.12 shows the use of complementary therapies by age and gender. Thirty three of the 40 subjects (82.5%) used complementary therapies. Of the male subjects, 6 (54%) used complementary therapies. In contrast, 27 of the 29 women, (93%) were users of complementary therapies. This difference is statistically significant (χ^2 $p = 0.016$).

Table 4.12 Use of complementary therapy by age and gender.

	Use of ComplementaryTherapy		
	Yes (%)	No (%)	Total
Total Number	**33 (82.5)**	**7 (17.5)**	**40**
Sex			
Male	6 (54.5)	5 (45.5)	**11**
Female	27 (93.1)	2 (6.9)	**29**
Age (yrs)			
20 - 39	7 (100)	0	**7**
40 -49	11 (100)	0	**11**
50 - 59	11 (64.7)	6 (35.3)	**17**
60 >	4 (80)	1 (20)	**5**

All the 18 subjects aged 20 - 40 years old were users of complementary therapies. Fifteen of 22 (68%) subjects over the age of 50 were users of complementary therapy.

4.3.2 Employment and educational qualifications

Table 4.13 Use of Complementary Therapy by Employment and Educational Levels.

	Use of ComplementaryTherapy		
	Yes (%)	No (%)	Total
Total Number	**33 (82.5)**	**7 (17.5)**	**40**
Employment			
Employed	12 (85.7)	2 (14.3)	**14**
Unemployed	21 (80.7)	5 (19.3)	**26**
Educational Level			
Secondary Education	26 (78.8)	7 (21.2)	**33**
Tertiary Education	7 (100)	0	**7**

Table 4.13 shows use of complementary therapies by employment and educational qualifications. The use of complementary therapies was similar in both employed and unemployed groups. However, 100% of the tertiary qualified subjects used complementary therapies compared with 79% of those with secondary qualifications

4.3.3 Patient satisfaction with complementary therapy

While this study was not intended to assess the efficacy of complementary therapies, Table 4.14 shows general patient satisfaction with such therapies. The use of complementary therapies was perceived to be of good benefit to 24 (72%) of the users. Three subjects (9.1%) felt that there was no benefit at all with 6 patients (18.2%) describing a marginal benefit.

Table 4.14 Patient Satisfaction among 33 users of Complementary Therapies

	Number (Total 33)	%
Good Benefit	24	72.7
Some Benefit	6	18.2
No Benefit	3	9.1

4.3.4 Influence of disease duration, disease category and EDSS on use of complementary therapy

Table 4.15 shows the use of complementary therapy by disease category, disease duration and disability (EDSS).

Table 4.15 Use of Complementary Therapy by Disease Category, Disease Duration and EDSS.

	Use of ComplementaryTherapy		
	Yes (%)	No (%)	Total
Total Number	**33 (82.5)**	**7 (17.5)**	**40**
Disease Category			
Relapsing Remitting	17 (94.4)	1 (5.6)	**18**
Secondary Progressive	9 (75)	3 (25)	**12**
Primary Progressive	7 (70)	3 (30)	**10**
Duration of Disease			
< 5 years	6 (75)	2 (25)	**8**
5 - 10 years	11 (84.6)	2 (15.4)	**13**
>10 years	16 (84.2)	3 (15.8)	**19**
EDSS			
1 - 5.5	14 (87.5)	2 (12.5)	**16**
6 - 7	11 (78.6)	3 (21.4)	**14**
7.5 - 9	8 (80)	2 (20)	**10**

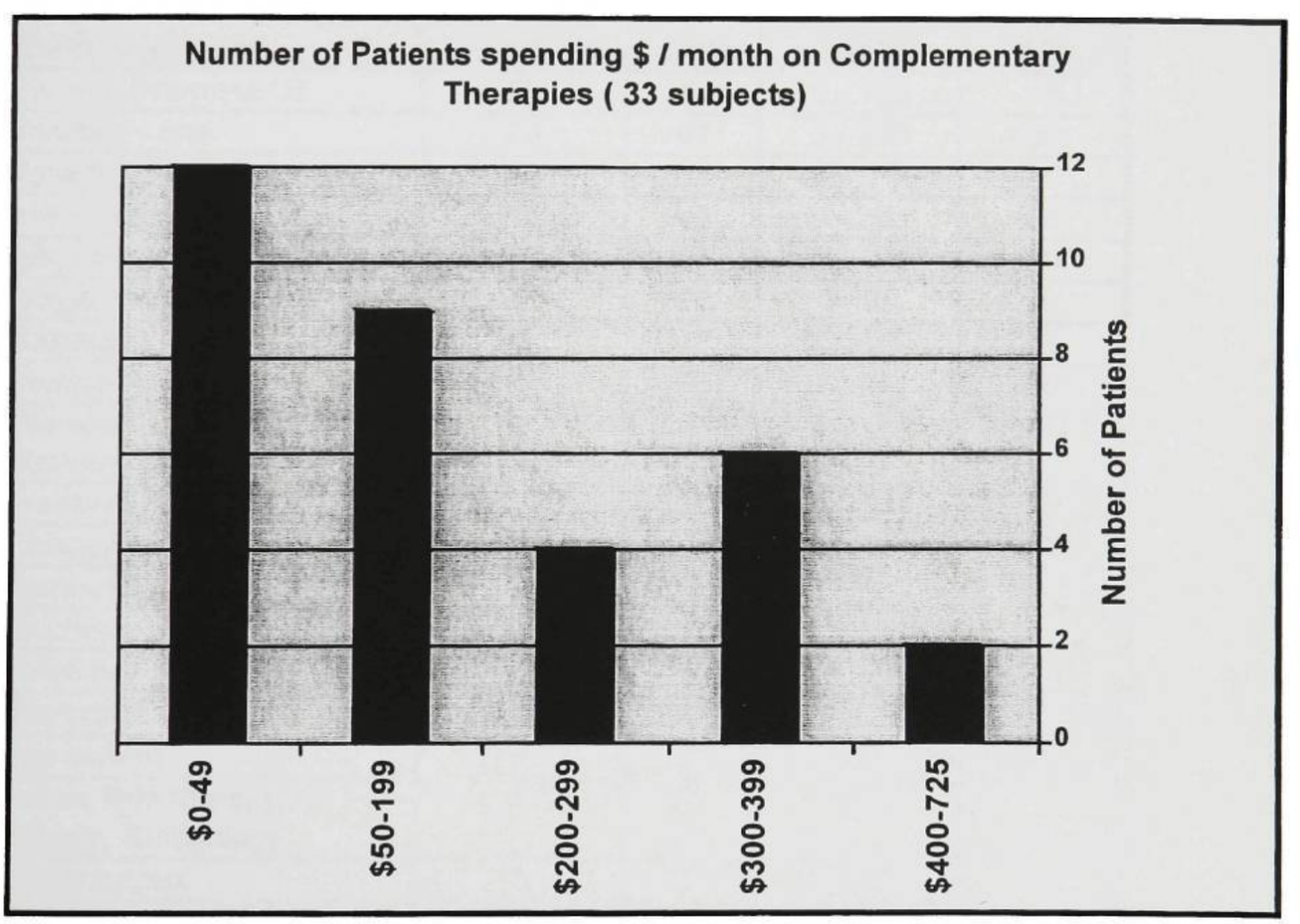
Interestingly, of the 18 patients with a diagnosis of relapsing remitting disease, 17 (94.4%) were using complementary therapies. This compares with 9 (75%)

of 12 secondary progressive patients and 7 (70%) of 10 primary progressive patients. Neither disability level (EDSS) or duration of disease had an appreciable impact on the use of complementary therapies.

4.4 Cost of Complementary Therapies

Figure 1 shows the number of patients spending differing amounts per month on complementary therapy.

Figure 1 Total cost of complementary therapy / person / month



The maximum amount that any one person spent in a one month period was $725 dollars. This individual was undergoing multiple complementary

therapies concurrently. This level of spending was maintained for a period of six months. Twelve (36%) spent less that $50 / month while 12 (36%) spent between $200 - $725 / month. Twenty four of 33 (73%) study participants used two or more complementary therapies.

Table 4.16 Use and cost to 33 users of complementary therapies

Complementary Therapy Used	Number using Therapy	%	$ Min - max / month	$ Median / month
Use of any therapy	33	*100*	0 - 725	100
Evening Primrose Oil	20	*61*	5 - 100	15
Vitamins - oral	20	*61*	5 - 200	20
Naturopathy	16	*48*	10 - 250	50
Acupuncture	14	*42*	5 - 200	80
Diet / supplements	7	*21*	5 - 180	20
Prayer/meditation	6	*18*	0 - 20	5
Massage	6	*18*	20 -100	55
Counselling	5	*15*	0 - 140	50
Vitamins- intramuscular/ intravenous	3	*9*	5 - 120	100
Aromatherapy	3	*9*	5 - 20	10
Picnogyl	3	*9*	80 - 120	100
Kambucha	2	*6*	5	
Oxichel	2	*6*	55	
Feldenkrais	2	*6*	10 - 30	
Marihuana	1	*3*	5	
Bee venom	1	*3*	30	
Colour light therapy, Polarity, Kinesology	1	*3*	55	
Shark extract	1	*3*	150	
Reiki	1	*3*	200	
Bowen technique	1	*3*	20	

Table 4.16 shows the complementary therapies used and the maximum and minimum and median cost to the consumers of each therapy. Thirty three of 40

patients (82.5%) used complementary therapies. The most frequently used complementary therapies by the 33 subjects were, 20 people (60%) using evening primrose oil, 20 (60%) using vitamins, 16 (48%) using naturopathy and 14 (42%) using acupuncture.

The cost of some therapies was relatively cheap such as evening primrose oil (median cost $15/month) when compared with picnogyl ($100/month) and intravenous vitamins ($100/month). A number of patients were using combination therapies and therefore incurred a greater cost.

The dosage and frequency of complementary therapies taken by people varied. There was often no recommended maximum dose and patients self prescribed many of the treatments listed above. Some had visited alternative health practitioners to have advice on which therapies should be taken. Patients used combinations of the above therapies with self regulated dosage/therapy schedule. Therapies were taken as a preventative measure, or when the MS was worsening.

All of the study participants were accessing mainstream services and only 7 of 40 were not users of complementary therapy. The use of complementary therapies was concurrent with mainstream services use by the large majority (82.5%) of this population which would indicate that these therapies are seen by the users as an adjunct for managing their MS. These results are similar to

other studies on the use of complementary therapies carried out by Singh et al., (1996) and Eisenberg et al., (1993)

4.5 Non users of complementary therapies

There were 7 of 40 (17.5%) non users of complementary therapies. Of these, 5 were males and 2 females, all were over 50 years of age (median 53) with 6 of 7 having a progressive form of MS (either SP or PP MS). None had tertiary educational qualifications with only one having employment. All these subjects accessed general practitioners and neurologists; 5 of 7 (71%) used MSSQ services; 4 of 7 (57%) used physiotherapy. Only 1 person of this group used community health services.

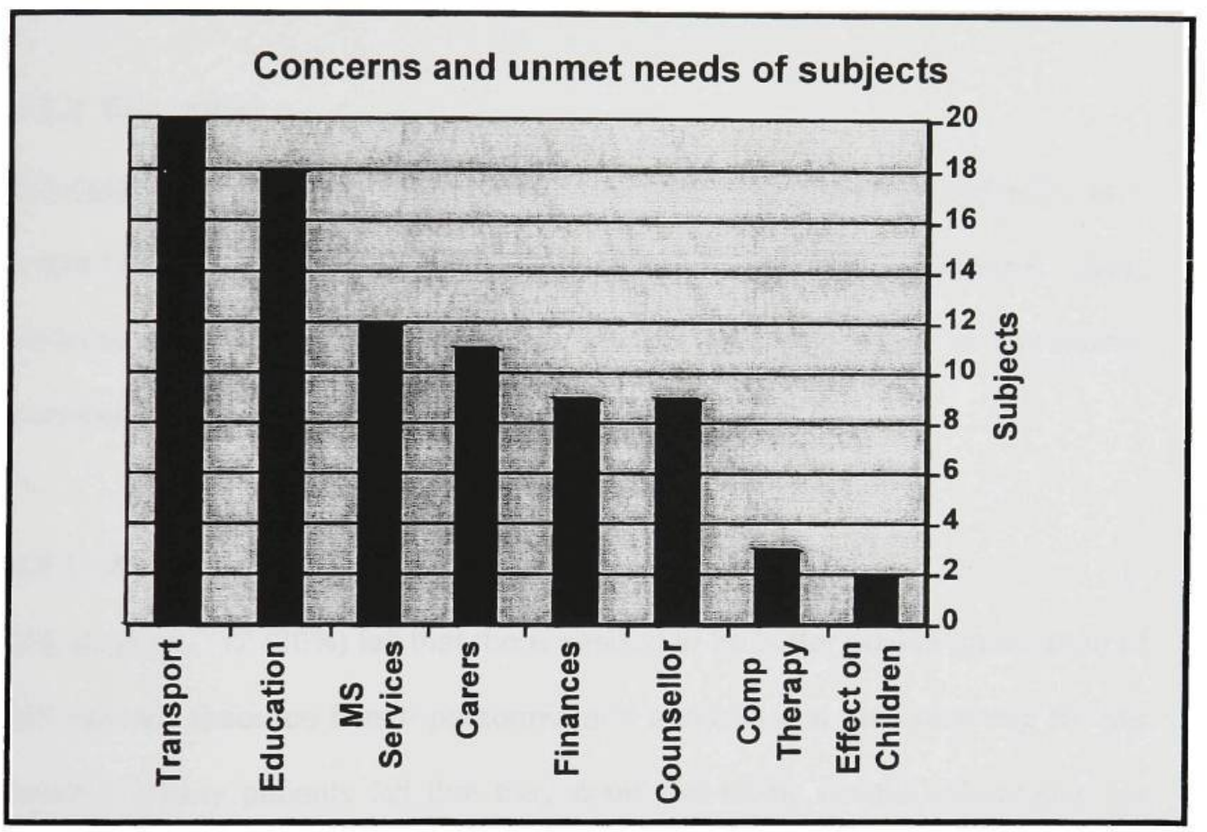
4.6 Unmet Needs of patients with MS

Unmet needs were not the planned focus of this study, therefore these issues were not investigated in depth nor 'followed through'. In the interview discussion, patients voiced personal concerns and personal or family needs in dealing with MS. Details of these issues are documented in Appendix C. These concerns have been categorised and are shown in Figure 2

Eleven of 40 (27.5%) patients expressed no concerns and stated they were satisfied with existing services. Perhaps these individuals had found alternative methods to deal with issues or had 'overcome' past concerns. These problems were no longer perceived as a problem for activities of daily

living. Or alternatively, their support network was sufficient to meet their personal needs. Some may have simply 'given up'. This would need to be explored in more detail.

Figure 2



4.6.1 Transportation

Transportation was raised as major concern by 20 (50%) of the subjects especially accessing transportation and the difficulties affording suitable transport vehicles or adjusting existing vehicles for wheelchairs. These were daily problems for people with MS who required transport in order to maintain a level of independence in carrying out activities of daily living, shopping, visiting friends and attending community facilities. Inadequate building access was also a problem, with a lack of, or inadequate, parking, ramps, rails, inadequate

space for mobility all of which restricted access in some public places. Geographical locations of both leisure and health facilities were a problem for those outside the main metropolitan area where facilities were not as readily accessible or available compared with the metropolitan area.

4.6.2 Education

Education about MS and disability was raised by 18 (45%) of the subjects as a major need for the community health services and health professionals. Many patients felt that they were unable to access general medical or community services that provided adequately informed services.

4.6.3 MS services

MS services, 12 (30%) felt that there needed to be better advice on location of MS specific resource health personnel and services and also planning for the future. Many patients felt that they could not easily access information on medical supplies, respite care and accommodation available for ongoing support.

4.6.4 Carers

Carers, often family members, were identified as a forgotten and overworked group. Eleven (27.5%) of patients felt that the expectations placed upon their family to provide 24 hour care were inappropriate and too taxing. The whole area of 'burden of care' is the subject of interest and research in the wider

community as the effects of chronic disease and shorter hospital bed stay days mean that families and carers are providing rehabilitation and caring roles.

4.6.5 Financial concerns

Financial concerns, were mentioned by 9 subjects (22.5%) because of loss of income and also the dependency on social services The cost of medical care is subsidised by government through Medicare and public hospitals, however, two people specifically mentioned the cost of magnetic resonance imaging which at the time of the this study, was not subsidised by private or Medicare insurance. This is no longer an issue since September 1998 as a rebate is now given by Medicare and health funds. Medical equipment (urinary catheters, pads, specialised cups and utensils for daily living) were either partially or not adequately funded for some people who were heavy users of these items.

4.6.6 Counselling

Counselling services and emotional support were stated as inadequate by 9 subjects (22.5%) with services costly and inaccessible for people with MS and their carers.

4.6.7 Complementary therapies

Complementary medicines and therapies were a concern. Some patients thought there should be refunds. Inadequate standards and safety issues of taking alternative therapies was also mentioned.

4.6.8 Child carers

Children of people with MS, were major 'care givers' to the person with MS for 2 patients, for personal and daily care. This was seen by one patient as undesirable although no alternative was perceived by the patient.

Chapter 5 Discussion

People need to have equitable, appropriate, affordable and accessible health care, as stated in the Ottawa Charter, which endeavours to:

> *".....advocate, enable and mediate for good health, equity on health care, ensuring equal opportunities and resources to enable all people to achieve their fullest health potential. This requires a supportive environment, access to information, life skills and opportunities for making healthy choices. People cannot achieve their fullest health potential unless they are able to take control of those things which determine their health."*
>
> (Ottawa Charter for Health Promotion 1986).

In order to provide this type of health service in Australia to those with MS, the system which delivers health services to those with MS must examine its current approach and ensure that it incorporates an intersectoral collaboration with patients, community and other agencies with an interest in the area. In the light of this principle, and with constraints that exist within the health care system in Australia, the present study has identified mainstream health services accessed, the prevalence of use and cost of complementary therapies to the consumer and identified areas of concern and health care practices of people with MS in South East Queensland.

The present study was of 40 subjects, and studied the use and cost of mainstream health services and complementary therapies, and the unmet needs of people with MS.

5.1 Demographics of the study population

Gender and age. The ratio of females to males (2:1) reflects the known gender ratio in MS and is consistent with Hammond's epidemiological survey of MS patients in Queensland (Hammond 1987). There was, however, a statistically significant difference between the age groups in the 2 studies, with an older population in the present study when compared with Hammond's population. This difference may be due to the selection process where no newly diagnosed patients (therefore younger) were enrolled into the present study. The younger newly diagnosed population are not well represented in this group.

In addition, the study participants were those who had had previous contact with the investigator in the care and monitoring of individual health care needs and therefore were those how lived within 4 hours drive of Brisbane city. It is difficult to know the regional differences that occur in MS population, that would make this study group more representative of the total MS population in Queensland.

Employment and educational qualifications. Thirty five percent of the patients (14 of 40) were employed although only two patients were over 65 years old,

indicating a high unemployment rate for those of working age. Of seven subjects who had tertiary qualifications (17.5%), three were now on a disability pension. These figures corroborate the findings of others the high impact that MS has on loss of income and unemployment (Bourdette et al 1993; Fawcett et al 1994; Asche et al 1995; Whetton-Goldstein et al 1996; The Canadian Burden of Illness Group 1998).

5.2 Disease categories, duration and severity

Disease categories, duration of disease and severity of disease. Proportions of patients with RR MS, SP MS and PP MS in the present study (45%, 30% and 20% respectively) are generally representative of the wider MS population and reflect the known incidence of disease types (approximately 66%, approximately 35% and 9 - 37% respectively). There is variation in percentage depending on the population studied (Weinschenker et al 1989).

The diversity in disability levels, disease duration and disease types within the study population provides insight into different areas of health services for people at varying stages of MS. This data shows current needs and concerns of this population that can be generalised to the population of MS sufferers in South East Queensland, recognizing that the newly diagnosed younger group are not well represented..

5.3 Use and cost of mainstream medicine.

The first hypothesis of the present study concerned the use of mainstream medicine. All study participants were using at least some mainstream medical services, with all participants having a neurological review every 12-18 months and seeing a general practitioner on a regular needs basis. This is an expected result as all participants were recruited through existing health networks. However, the use of health services by people with MS in this study population varied with individuals, depending on disability and emotional and cognitive requirements, as has also been documented by Hainsworth (1994).

Neurologists and general practitioners All patients were accessing mainstream medical providers on a needs basis. Specialist neurologists were accessed by all study participants. This is a recommended practice, as MS can be difficult to diagnose (Pender 1996) and the monitoring of the disease course is an important part of assessing and managing the individual's MS. General practitioners were accessed on a needs basis, if the person with MS had other medical conditions and health concerns requiring medical attention. A study in patients with MS in New South Wales confirmed the important role of the family physician rating them as the most important health professional in their ongoing management of MS (Black et al., 1994).

Enteen (1995) showed that the majority (56%) of patient with MS in the USA identified their neurologist as the primary care physician. In the USA, the health

insurance system means that the medical management of MS does not necessarily rely on the general practitioner. However, in Australia, access to Medicare means that patients can access all health services that are appropriate without incurring out of pocket expenses.

However, services were not 'without cost' to the community, as the payment to service providers was through the Medicare levy. The cost of MS to the community has been documented in other countries (Canada, United Kingdom, United States). In these countries, a large part of the health and social services budgets for people with MS comes from revenue drawn from the community (Bourdette et al 1993; Whetton-Goldstein et al 1996; Hatch 1996; The Canadian Burden of Illness Group 1998). It is highly likely that a similar situation exists in Australia, with MS having a considerable economic impact on the community, although the investigator is unable to estimate what this cost may be. However, by identifying how frequently people with MS are utilizing Medicare funded facilities, it may help health economic planners to spend the health dollar more efficiently for those with MS.

Patients with private health insurance or wealth can also access neurologists and practitioners who charge for services, at a cost to the consumer. However, this has not been documented in the present study, though the comparison of such a population with the present study would be informative.

Physiotherapy is considered an important part of maintaining potential well being for a person with MS and is recommended by neurologists. In the present study, both males (63.6%) and females (55.2%) were accessing physiotherapy. These patients believed that physiotherapy had an important role in the management of their MS. This is supported by the research of DiFabio et al (1998) which showed that rehabilitation using regular physiotherapy programmes led to significantly fewer symptoms, preservation of physical and cognitive function and improved quality of life. In the current study, employed people used physiotherapy less often than the unemployed. This may reflect the fact that only the mobile and well MS population remains in the workforce. The use of physiotherapy may be perceived by the person with MS, and perhaps the carer, as belonging to the more disabled person.

Access to the physiotherapist increased as disability worsened. Those with an EDSS score of 1 - 5.5 (mobile) used physiotherapy less frequently than those with an EDSS score of 7.5 - 9 (non-mobile) (44% vs 70% respectively). Similarly, as disease duration increased there was an increase in the use of physiotherapy (50% for patients with a disease duration of < 5 years to 68.4% for patient with disease duration of > 10 years).

Community services were used by a significantly greater percentage of unemployed persons (54%) than employed (7%). Most community services provided either nursing care or personal attendants for home help on a daily

basis, which would not be needed for those who were working or less disabled. Another factor in the use of community services is whether the person with MS has available family members who take on the carer role and therefore reduce the need for assistance from community services. This is not detailed within the parameters of this study.

5.4 Support services

The Multiple Sclerosis Society of Queensland (MSSQ) was used frequently by a majority (80%) of persons interviewed, with the remainder not using the services at all. All age groups had over 70% usage of the MSSQ. There was increased use of MSSQ as disease duration and EDSS increased, with 100 of those who were wheelchair bound accessing MSSQ services compared to 62.5% of ambulatory people with MS. The wide variety of study participants using the services of MSSQ may reflect the diverse support offered for the person with MS. The needs of people vary during the course of their MS and accordingly, support services of MSSQ are made to meet the broad needs of the total population of MS sufferers in Queensland.

The MSSQ is the specialist support service to address specific needs and respite for people in Queensland and northern New South Wales with MS and also for their carers. The MSSQ offers accessible and affordable services via telephone with a 1800 toll free telephone available to anyone in Queensland. Resources and help for specific quality of life issues, such as psychologist

support, occupational therapist and home assessment advice, information on how to apply for pensions and work intervention counselling are available at an affordable cost ($10 a year registration).

The services of the MSSQ appear to play a major role in the care and support of people with MS.

5.5 The use of complementary therapy

The precise extent of the use of alternative therapies in Australia is yet unknown. It appears to be very large, with an estimated one fifth of the Australian and United States population visiting alternative practitioners each year (Komesaroff et al., 1998). The second hypothesis of this thesis concerned the use of complementary therapies by people with MS and the present study confirmed that a significant proportion (82.5% or 33 of 40) of participants used complementary therapies.

Previous studies have shown that between 20 - 90% of patients with incurable chronic diseases use complementary therapies (Cronan, 1989; Eisenberg et al., 1993; Donnelly et al., 1985; Singh et al., 1996; Risberg et al., 1995). It is difficult to speculate with certainty why MS sufferers are in the upper percentage of users of complementary therapies. The uncertain course of the disease may give more opportunity for hope of control over the disease, or with

the disease being one of the younger working age population there may be a different approach to medical care and self choice for treatment.

The use of complementary medicines has been detailed in a number of chronic debilitating diseases. In a study of HIV, patients using complementary therapies, had a greater sense of control and self management of the disease course, but ultimately, the clinical outcome was not impacted by these therapies (Singh et al., 1996). The use of complementary therapies by cancer patients has also been documented by Risberg et al (1995) who showed 45% of cancer patients used such therapies, although it did not influence survival amongst these patients. Cronan et al found that as many as 90% of patients with musculoskeletal disorders were accessing complementary therapies. Use of complementary therapy is also increased in patients with asthma (Donnelly et al., 1985) The widespread use of complementary therapies has been established by these studies.

In the current study population, all those who were users of complementary therapy were also accessing a conventional medical practitioner, either a neurologist or general practitioner. Thus, the fourth hypothesis of this study, that people with MS are using complementary therapies as an adjunct therapy with mainstream therapies in managing their MS has been found to be correct in this population. Donnelly et al documented that 76% of subjects were satisfied with both orthodox and alternative medicines and were not disgruntled

with orthodox medicine (1985). Eisenberg et al., (1993), in a national survey of the use of unconventional medicine in the USA, found that all patients with a primary diagnosis of cancer, if using an alternative therapist, always also saw a mainstream medical doctor for this condition.

It is now well documented that a substantial number of people with illness will access their mainstream medical therapy concurrently with alternative therapies (Fawcett et al, 1994). This is confirmed in the present study with 82.5% of patients using complementary therapies alongside mainstream health services.

The high use of complementary therapies in the multiple sclerosis population agreed with findings in other chronic incurable diseases of arthritis, HIV and cancer.

5.6 Users of complementary therapies

Of the 11 males in the study, only 6 (54%) used any form of alternative therapy, this is in contrast to 27 of 29 (93.1%) of females ($p=0.016$). This is an interesting observation and may reflect the characteristics of differing approaches taken by males and females in managing their own disease and their willingness to take 'risks' in self prescribing non proven therapies. It may demonstrate that females have a greater need for control over disease outcomes. This area would need to be investigated further to determine underlying reasons for this occurrence.

All subjects in the present study who were aged between 20 - 40 were users of one or more complementary therapies, while 6 of 17 (35.3%) persons aged 50 - 59 did not use any therapy at all. This could be explained by the fact that of the 6 people between the ages of 50 - 59 who were not using complementary therapy, 5 (83%) were males. Another possible explanation, is that the older generation (50 - 59 year olds) may have a more conservative approach to medicine and adhere to mainstream medical advice and let 'the disease take its course'. Alternatively, the lack of use of complementary therapies in older patients could reflect the stage of the disease. Of the 6 patients in the 50 - 59 age group who did not use complementary therapies, 2 had SP MS and 3 had PP MS. It is possible that those with a progressive form of MS may have a different approach to their disease management.

In this study, 94% of people with RR use complementary therapy compared to 75% of SP MS and 70% of PP MS as shown in Table 4.15. There was no appreciable impact of disease duration or EDSS on use of complementary therapies. As the natural course of RR MS is for remissions and relapses, it may offer more hope to people with this type of MS to take control of the 'ups and downs' of their disease progression, believing that the complementary therapy will give some benefits. Except in the very long term, it would be difficult to assess (in most RR MS patients) whether a complementary therapy was having much of an effect, as the relapse rate is often fairly low (1 - 2 per

year) and relapse signs and severity can vary significantly from one relapse to another.

5.7 The cost of complementary therapies

The third hypothesis addressed cost of complementary therapies. In the present study there was a wide range of cost to the consumer of complementary therapies, ranging from $0 - $725 per month. This data would concur with findings of a New South Wales study of cancer patients by Begbie et al (1996) documenting $0 - $20,000 per year range of cost of complementary therapies. Approximately one third (12 of 33) of users spent less than $50 per month. Except for the unusual treatments used by one individual, the majority of therapies such as acupuncture, vitamins, evening primrose oil and massage were relatively inexpensive. For some users of complementary therapy the cost was small, vitamins and evening primrose oil costing less than $20 / month. The median cost of these therapies was less than $60 per month.

As discussed earlier, the use of complementary therapies is a common practice in chronic diseases, often alongside prescribed mainstream therapies. The use of complementary therapies in the United states was over $US10 billion (Eisenberg et al 1993), with an estimated expenditure by Australians per year of over $AUS1 billion (MacLennan et al 1996). With this amount of money spent on unprescribed medications with unknown safety outcomes, health

providers and health administrators have a responsibility to monitor and protect the public health of its constituents.

There is often insufficient or negligible scientific information available about complementary medicines to allow any sort of "informed decision". Many or most of these substances are allowed into the market as "foods" and therefore do not have to meet the stringent regulations of drug evaluation at government level. It is for this reason, at least as far as safety is concerned, that adverse drug/substance reporting is so essential. This of course still does not deal with the more difficult area of efficacy of the therapeutic agent.

5.8 Unmet needs and concerns

The major concerns raised by people with MS related to activities of daily living (transport, parking), the lack of knowledge about MS within the community (both of health providers and community groups), difficulty of knowing which services were available for support and how to access appropriate health support networks, financial difficulties and constraints for the more disabled persons (purchase of pads, catheters), the large burden of care which fell on family members (parents, partners and children). These issues should be addressed as suggested in the Recommendations Chapter 6.

5.9 Summary

The results of the study indicate that there is a high use of complementary therapies amongst people with multiple sclerosis. It is also evident from the participants in the present study that complementary therapies are used as an adjunct therapy to mainstream medicine. People with MS in this study were all using mainstream medicine, had increasing use of physiotherapy and MSSQ as disability worsened and were more likely to use community services when unemployed.

For some patients, complementary therapies were consumed or accessed at a small monthly economic cost, however, for others the economic impact was substantial. The use of complementary therapies as an adjunct to mainstream medicine has been documented in this study, and as Hensley and Gibson (1998) have stated:

> *"ineffective or unsafe therapies should be abandoned, and unproven interventions should be evaluated in high quality clinical trials..... an evidence based approach to health care"*

People with MS are exercising choice and decision making by using mainstream and/or complementary medicines. There needs to be an open communication between the mainstream health professional and the consumer so that relevant information about potential adverse reactions can be given.

Chapter 6 Recommendations

◊ Medical practitioners and other health professionals should be aware of the high use of complementary therapies by people with MS, and document and discuss these therapies with patients.

◊ As many patients do not openly discuss complementary therapies with the mainstream health provider it is important that patients be asked about the use of complementary therapies, so that potential adverse reactions, if known, can be discussed and avoided.

◊ Health institutions and government bodies need to make known risks and adverse reactions of 'natural' and 'unproven' substances so that an individual can make an informed decision about managing his or her disease.

◊ All health professionals and also any prescribers of complementary medicines should be aware that any adverse events should be reported to ADRAC (Adverse Drug Reactions Committee). This fact should be widely promulgated to any potential users of such agents.

◊ This research has identified that a considerable amount of money is spent on complementary therapies by people in the community with multiple sclerosis. More research is needed to determine effectiveness and side effects of these therapies.

◊ Existing mainstream health services provide many services but it appears that these may not be utilised to the fullest potential. Access to these services appears to be needed at a community level and methods of providing accessible health care in the community with intersectoral collaboration need to be explored.

◊ For complementary therapies that are demonstrated to be effective and safe the question of reimbursement by Medicare Benefits Schedule needs to be addressed.

◊ Education of health professionals about MS needs to be addressed. MS specific courses could be offered in health professional training for General Practitioners and other health professionals. One such course for post graduate and undergraduate nurses currently exists at the Queensland University of Technology.

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APPENDIX A

PEOPLE WITH MULTIPLE SCLEROSIS -

MAINSTREAM HEALTH SERVICES AND

COMPLEMENTARY THERAPIES QUESTIONNAIRE

Thankyou for participating in this study. As already mentioned, the data collected from this study will remain confidential and secure. I appreciate you/time with this project and would like you to answer the questions as you feel comfortable. There are some questions that require a yes/no answer while others are left open for your comments and answers.

There are questions about using alternative therapies before you got Multiple Sclerosis. Also some questions concerning what therapies were used once you were diagnosed with MS. Finally some general information that will help with the general understanding of the participants in the questionnaire.

The aim of the questionnaire is to try and identify what different sorts of alternative (not prescibed by your GP or Specialist Doctor) treatments people are trying. This is not research into whether these different therapies work, but rather try to find out what diverse treatments are used by people with MS and the cost of these medications and treatments.

Consent to participate in Masters of Public Health Study on:

"The use of health services / therapies in people with Multiple Sclerosis."

I _____
understand that participation in the above project is entirely voluntary and all information collected will remain confidential. Data will be coded so that my identity will not be revealed.

Signed: _____ Date: _____

Witness: _____

Health Services Accessed by People with Multiple Sclerosis

Code: _____ Date of Interview: _____

NAME: _____

DOB: _____ Ethnicity: _____

Address: _____

Postcode: _____ Sex: M / F

Birthplace: _____ Moved < 10yrs old?: Y / N

If yes, to: _____

Employment: Y / N Occupation: _____

Highest Educational Qualification: _____

Comments: _____

_____

Medical History

Year MS diagnosed: _____

Initial symptoms: _____

Classification of MS:

1. Relapsing/Remitting 2. Primary Progressive 3. Secondary Progressive

Comments: _____

Current EDSS: _____

Other medical conditions: Y / N

if Yes then list diseases: _____

Family History of MS: Y / N

if yes, then relatives affected: _____

_____

Services Accessed:

- General Practitioners Yes/No

  Frequency: _____

  Cost: Nil Cost / $_____

- Specialist Physicians Yes/No

  Frequency: _____

  Cost: Nil Cost / $_____

- MS Society Yes/No

  Frequency: _____

  Cost: Nil Cost / $_____

- Physiotherapist Yes/No

  Frequency: _____

  Cost: Nil Cost / $_____

- Community Health Services Yes/No

  Frequency: _____

  Cost: Nil Cost / $_____

- Hospital Outpatient services Yes/No

  Frequency: _____

  Cost: Nil Cost / $_____

- Other: Yes/No

  _____

Have you used any of the following ? :

- Evening Primrose Oil Yes/No
- Acupuncture Yes/No
- Dietary Yes/No
- Naturopathy Yes/No
- Vitamin therapy Yes/No
- Counselling/Psychologist Yes/No
- Spiritual/Church Yes/No
- Other: Yes /No

(Aromatherapy, Chinese Traditional Medicine, Crystal Healing, Herbal, Massage, Meditation, etc) _____

_____

For each service/therapy accessed or used please detail the following:

Therapy used:

- Date commenced (approximate) _____
- Was this therapy used prior to onset of MS - Yes / No
- Dose and frequency _____
- Route _____
- Cost per unit/visit _____
- Duration of treatment _____
- Beneficial? No Some Moderate Good

Are there any services for people with MS would you like to see available?

eg: Medical, social, support groups, transport, access, free/discount catheters etc.....anything you would like!

What health services for people with MS would you like to see changed?

What are the major service areas that are of concern to you ?

Thankyou for your participation with this questionnaire.

APPENDIX B

追风活血片

（糖衣） 80片

本品系根据古代名临床总结验方，采用地道药材、乳香、没药、杜仲、防风、独等，十五味用科学方法制成。具有舒筋活血、散风祛寒之功能为追风活血之良药。

适用范围：

风寒串入经络、腰胳膊疼痛、四肢软弱无力等症。

服法、用量：

成人每次服四片，日服二次，温开水送下。

禁忌：孕妇忌服。

追风活血片（成份）

桂枝	6%
乳香	8%
独活	6%
自然铜	5%
麻黄	5%
杜仲	12%
没药	8%
年建	6%
防风	8%
木瓜	6%
怀牛膝	8%
地风	6%
羌活	6%
甘草	5%
冬密	5%

中国吉林四平制药厂出品

CHUI FENG HUOHSUEH PIEN

(Sugar Coated) 80 Tablets

This tablet is scientifically prepared from Chinese precious medicines such as mastix, myrrha, cortex eucommiae, radix sileris, radix heraclei and so on according to the prescription by summing up the clinical experiences of the ancient famous physicians. It is efficacious in relaxing the tendons and ligaments, relieving rheumatism, and a good medicine for carminative and promoting blood circulation.

Indications: Rheumatic pains in loins, legs and arms, feeb leness in limbs, etc.

Dosage: For adults: 4 tablets twice daily with lukewarm boiled water.

Caution: Not to be taken by pregnant women.

CHUI FENG HUOHSUEN PIEN (*Ingredients*)

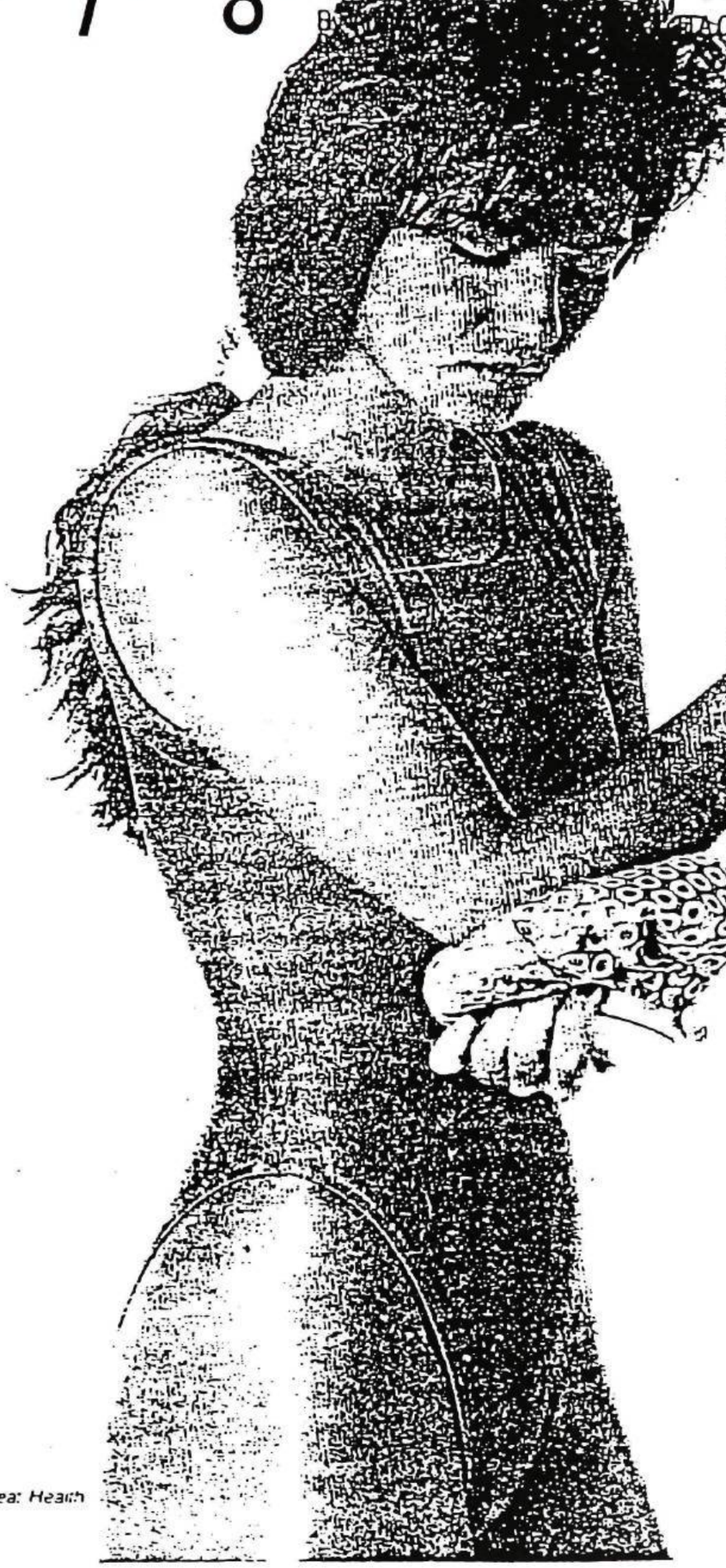
Ramulus Cinnamomi	6%
Mastix	8%
Radix Heraclei	6%
Pvritum	5%
Herba Ephedrae	5%
Cortex Eucommiae	12%
Myrrha	8%
Niem Chien	6%
Radix Sileris	8%
Fructus Chacnomelis	6%
Radix Achyranthis Bidentatae	8%
Ti Fong	6%
Rhizoma Notopterygii	6%
Radix Glycyrrhizae	5%
Honey	5%

MANUFACTURED BY
SIPING PHARMACEUTIC WORKS
JILIN CHINA

Jude -

Is Pycnogenol The Fountain Of Youth?

B[illegible] T.C.B.N.



Lost a step or two? Can't read the morning paper as well? Forgot your best friend's phone number? Joints stiff and aching? Any new wrinkles? What could be the solution to these problems? Pycnogenol (pronounced *pik nah' je nol*) might be the answer.

Today, Pycnogenol is being used against heart disease, circulatory disorders, skin problems, brain dysfunction, stress, inflammation, sports injuries, hay fever, diabetic retinopathy, cancer, arthritis and aging, to name a few.

These conditions are caused, at least in part, by free radicals. But what are free radicals?

Free radicals destroy cells by damaging their membranes. The cells can't function properly, nor reproduce. Nutrients can't get in and waste can't get out. The cells steadily decrease in number, causing the tissues to lose function. This damage accelerates aging.

Free radicals can fuse molecules together, making the molecules unable to function properly. In the skin, this causes a loss of elasticity and smoothness, leading to wrinkles. Free radical damage is what we recognize as aging, and, according to Dr. Jeffrey Bland, is implicated in more than 60 diseases.

By eliminating (breaking down) these free radicals, we can assist our bodies in returning us to a healthy state, to live longer, happier, pain-free lives. We all have free radicals in our bodies and we can eliminate them by taking antioxidants.

The accumulation of cholesterol (due to the modification or oxidation of low density lipoproteins — LDLs) can be prevented, or slowed down, by antioxidants.

Pycnogenol is a powerful scavenger of free radicals and an antioxidant. It can counteract the effects of aging

and acts as a protector against today's environmental toxins (such as radiation, pesticides, pollution, heavy metals, etc.). Made from the bark of *pinus maritimus* (French maritime pine), Pycnogenol is pure and natural, having no solvent residues or additives. Taken orally, it works with vitamin C to enhance vitamin C's activity.

Pycnogenol is not new. In 1535, Jacques Cartier (exploring what is now Canada) saw many of his crew members die from scurvy. The local Indians taught him to prepare a brew made from the bark and needles of the Ameda pine, which returned the men to health.

400 years later, Professor Jacques Masquelier discovered that pine bark (Pycnogenol's source) contains a special class of water-soluble bioflavonoids (proanthocyanidins). These bioflavonoids have powerful antioxidant properties and can help rid the body of free radicals.

Pycnogenol inhibits formation of the enzymes that cause allergies and inflammations, thereby reducing histamine production. For this reason, many people use Pycnogenol in the treatment of allergies. In fact, in Finland, it is popular for use against hay fever.

Pycnogenol is also helpful in improving circulation. When you are injured or have muscle cramps, the damaged area needs more oxygen. This demand must be met by your capillaries, (tiny blood vessels which bring in fresh oxygenated red corpuscles and carry away used blood).

To do this rapidly and efficiently, your capillaries must be healthy. In the case of injury, your capillaries are damaged, resulting in swelling and bruising. The sooner your capillaries return to normal, the sooner bruises, swellings and pain disappear, the sooner you get back into action. Your best hope is to keep your circulatory system in as healthy a state as possible and when an injury occurs, to help it respond quickly.

Helping the lining of arteries resist attachment by mutagens (which can cause cardiovascular disease), Pycnogenol restores the strength of the capillaries and improves circulation, making it easier for each cell to get the nutrients needed. Improved circulation is especially valuable to stroke victims, diabetics, arthritics, smokers, women taking oral contraceptives and people with swollen, edematous legs.

Pycnogenol also has a unique ability to bond to collagen fibers. All cells in the human body are glued together with collagen. Pycnogenol helps these collagen fibers rebuild their cross-links and reverse some of the damage done over the years by injury and free radical attack. Further, Pycnogenol inhibits the body's enzymes that break down collagen. Pycnogenol helps return flexibilty to skin, arteries, capillaries, joints and other tissues by restoring collagen.

The human body cannot survive without vitamin C. Pycnogenol actually activates vitamin C and helps put it to work fast, continuing to work on its own long after vitamin C passes out of the body. Pycnogenol works to maintain the integrity of blood vessels, particularly the capillaries, and exerts a powerful anti-inflammatory, antiinfective, antiaging effect.

Vitamins C and E have long been regarded as effective antioxidants. According to Richard Passwater, Ph.D., in standard *in vitro* studies (test tube, not in the human body), Pycnogenol proved to be 60 times more powerful than vitamin E and 20 times more powerful than vitamin C in the ability to scavenge (neutralize) free radicals. In addition, Pycnogenol remains in the blood stream for 72 hours (unlike vitamins E and C which pass quickly through the system), thus giving extended free radical protection.

Studies show that Pycnogenol is rapidly absorbed and distributed throughout the body: within 20 minutes, much of Pycnogenol is absorbed and on its way to tissues; within one hour of ingestion, it can be detected in saliva. Because it is acidic, Pycnogenol is highly compatible with human digestion.

In addition, according to Passwater, Pycnogenol is a nonantigenic, nonmutagenic, noncarcinogenic and nonteratogenic substance.

Unlike virtually all other dietary products, the beneficial effects of Pycnogenol cross the blood brain barrier to protect the blood vessels in the brain from oxidation, thus having strong possibilities in fighting senility.

Pycnogenol has long been used in France, Finland, Holland, Germany, Italy, Singapore, Korea, Argentina and Switzerland and has just recently been marketed in the United States.

In many countries, women take Pycnogenol as an oral cosmetic to fight wrinkles before they begin. It helps keep their skin elastic, smooth and more wrinkle-free by restoring the skin's collagen and protecting it from free radical attack and enzymatic degradation.

In today's fast paced, highly stressful, polluted environment, diseases from free radical damage are a fact of life. To combat this damage, free radical scavengers are essential. For good health, antioxidants such as Pycnogenol, vitamins C and E are critical for daily usage. After all, "An ounce of prevention is worth a pound of cure."

The benefits of Pycnogenol are many. Pycnogenol has been shown to:

- Retard aging
- Improve circulation
- Improve vision acuity
- Improve flexibilty
- Reduce wrinkling of the skin
- Aid in resistance to bruising
- Reduce mental deterioration
- Reduce risk of cancer
- Reduce risk of heart disease
- Reduce risk of vascular disease
- Reduce risk of stroke
- Reduce risk of phlebitis
- Reduce inflammation in arthritis
- Reduce inflammation in sports injuries
- Enhance immune resistance
- Reduce frequency and severity of colds
- Enhance faster healing
- Subdue allergic reactions
- Subdue PMS
- Enhance energy
- Reduce fatigue

Dr. Cichoke is a chiropractic physician in Portland, Oregon and author of over 100 scientific articles. He is a well-known writer, lecturer and researcher on health and nutrition.

binds very tightly to collagen, including those that are integral to the blood-brain barrier, producing a "super-collagen" much more resistant to enzymatic breakdown.

Studies reveal that pycnogenol has the ability to transport itself inside the nervous system to protect against damage to nervous tissue made up of unsaturated fatty acids which are susceptible to free radical damage.

In addition to powerful antioxidant activity and ability to cross the blood-brain barrier, pycnogenol stays in the blood stream for approximately 72 hours. However, vitamins E and C pass through the system quickly and provide only minimal protection against free radicals, since free radicals are produced constantly in the human body.

Scientists at the Okayama University Medical School and along with the Faculty of Pharmaceutical Sciences at Kyushu University have confirmed that pycnogenol (proanthocyanidin) is 50 times more powerful than vitamin E as a free radical scavenger. Dr. Masqueller's experiments with vitamin C have shown that pycnogenol is 20 times more powerful than vitamin C as a free radical scavenger.

All of the experiments on pycnogenol mentioned above did not produce any adverse side effects. Pycnogenol is very well tolerated and non-toxic even at high doses.

Pycnogenol should be taken daily to prevent the onset of free radical induced disorders. 1.5 to 3mg per kilogram (2.2lbs) of body weight is required for two weeks to saturate the tissues, then only 20 to 60mg.. per day is needed to maintain tissue reserves. Massive doses need not be taken.

To sum up, pycnogenol is highly bioavailable, absorbed immediately from the stomach into the blood stream and attaches itself to the cellular walls. Pycnogenol is non-toxic and remains in the system for 72 hours while it traps and neutralizers free radical molecules showing powerful free radical scavenging abilities. Pycnogenol prevents the peroxidation which accelerates the aging process. Pycnogenol is able to cross the blood-brain barrier providing antioxidant protection to brain and nerve tissues. It is effective against internal bleeding (for cessation of abnormal menstrual bleeding) and cramps. It strengthens and normalizes collagen and the vascular system.

Pycnogenol has many impressive clinical studies demonstrating favorable effects against arthritis, bruises, capillary fragility and other circulatory problems, such as varicose veins, nightly calf cramps, and cold feet and fingers. It also acts as an anti-inflammatory agent making it useful in the treatment of hemorrhoids, swollen joints and sports-related injuries. It has been found effective against liver oxidative problems from exposure to pollutants. Pycnogenol appears to hold a special place not only in the symptomatic treatment of diabetic retinopathy or hemorrhagic complications, but also in the prevention of complications following cataract operations in diabetics.

Living in modern society, most of us can't escape from the environmental pollutants and are afflicted by various maladies related to free radical damage. Premature aging, malfunctioning of circulatory, nervous and immune systems all result from free radical damage in the body. To fight the environmental pollutants and health problems we have today, pycnogenol, vitamins C and E, beta-carotene, and bioavailable oxygen are highly recommended to take daily, along with a diet high in fiber. After all, prevention is the best medicine.

Steve S. Choi is a Certified Nutritionist and a member of SCN(Society of Certified Nutritionists). He has studied nutrition extensively and presented scientific papers during the last five years.

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Pycnogenol

The Most Powerful Antioxidant and Free Radical Scavenger Ever Discovered

By Steve S Choi, B.S., C.N.

Free radicals are defined as unpaired electrons which have a strong driving force to combine with adjacent molecules, thereby causing permanent damage to cells. Commonly, free radicals are produced in the body where good oxygen molecules are transformed into a highly reactive, unstable form of oxygen with an unpaired electron.

Without control, these free radicals can multiply geometrically by a process called free radical chain-reaction. Free radical chain-reaction releases thousands of free radicals. It is further accelerated by environmental pollutions, cured meats, smoking, alcohol, food additives, pesticides, herbicides, chemotherapy, x-rays, asbestos, stress, physical trauma, and other man-made pollutants. Even the things we do everyday, such as exercise, initiates free radical chain reaction.

These reactive substances, superoxide (O_2) and related free radicals are highly toxic. They can attack and ultimately destroy any material including genetic material (DNA). The reported effects of excessive free radicals in the human body would be: damage to cell membranes, macro-molecules and DNA, affecting virtually every kind of nervous tissue; increased susceptibility to infection; inability to deal with stress; and overall degeneration of the body.

Dr. Jeffrey Bland, Ph. D., who is a renowned nutritionist and chemist, states that more than 60 diseases are traceable, at least in part, to an excess of free radicals. These diseases include among many others, Alzheimers, Parkinson's, aids, cancer, arthritis, rheumatism, cataracts, kidney and liver disorders, retinitis, all forms of vascular disorders including angina, heart diseases, collagen deterioration(aging), senility, premature aging, diminished life span, and stroke. Edema, phlebitis, swollen extremities, cold toes and fingers, all of which are associated with poor blood circulation, can be traced to the destructive effects of free radicals.

Fortunately, nature has provided us with natural protectors called antioxidants or free radical scavengers. These antioxidants donate electrons to unpaired free radicals thereby stabilizing and inactivating them. Some of these free radical scavengers are vitamin E and C, beta carotene, peroxidases, catalase, superoxide dismutase, glutathione peroxidase, coenzyme Q_{10}, pycnogenol and many others. Using these antioxidant supplements can help build up the body's defense system and may even slow down the aging process.

Pycnogenol has been found to be the most powerful antioxidant of all those studied. Pycnogenol is the trade name of a natural substance, proanthocyanidin, which is extracted from the bark of pine trees (Pinus pinaster).

Pycnogenol contains 85% proanthocyanidins (or procyanidins) by weight and has chemical and pharmacological characteristics similar to the family of flavonoids, yet has profound differences. For instance, pycnogenol is very soluble in water, whereas flavonoids are not readily dissolved. Pharmacologically, pycnogenol distinguishes itself from flavonoids by its bioavailability and lack of toxicity.

Pycnogenol has been tested in many clinical trials, double blind and open studies in order to demonstrate its efficacy and tolerance in the claims, such as raising capillary resistance, reduction of capillary permeability, treatment of chronic venous insufficiency, retinopathies and capillary fragility with bleeding. These experiments support pycnogenol as effectively preventing and treating free radical caused ailments.

In 1965, Jack Masquelier, of Bordeaux University in France, conducted research on pycnogenol with 45 patients suffering from skin diseases or phlebological illnesses such as eczema, ulcerated varicose veins, etc. The result was 140% increase of capillary resistance with patients on a single dose of 100mg of pycnogenol. This research exhibited pycnogenol's long lasting activity in the fundamental treatment of microcapillary disturbances, which acts not only on the perfusion of capillaries, but also on the structure itself of the capillaries.

Biochemical experiments were conducted in an attempt to explain the strong vascular protecting effects of proanthocyanidin. It was discovered that Pycnogenol fixed on the collagen, one of the main supporting proteins of the body. These experiments have been confirmed by pharmacologists at the University of Paris.

Dr. G. Feine-Haake in West Germany, who specializes in internal medicine, treated 110 patients (30 - 92 years; average age being 65) with 15mg of pycnogenol, daily for nightly cramps, tension, and heaviness in legs, status varicose, smarting while standing, hemorrhoid and post thrombotic edema. All these patients had dramatic improvement in clinical signs and symptoms (70 - 93%) in their conditions. he noticed no toxicity with 6 months of pycnogenol treatment and its high solubility offering effectiveness even in small amounts.

Pycnogenol is found to be an important protector for the eyes in diabetic individuals, who are susceptible to hemorrhagic diseases of the eye.

Dr. G. Maynard et al in France treated 40 patients with diabetic retinopathy with 80 - 120mg of pycnogenol daily initially, than 40 - 80mg daily for 6 weeks to 4 months. The results was that pycnogenol treated not only symptomatic diabetic retinopathy or hemorrhagic complications, but was also effective in preventing complications following cataract surgery in diabetics. He noticed patients' pycnogenol tolerance was excellent without any side-effects during treatments.

Further tests have shown that pycnogenol is effective against bleeding. For example, in the case of microbleeding, as a consequence of contact lenses in opthalmology, pycnogenol strengthens and normalizes the capillary resistance of the small blood vessels of the eye. The result is a cessation of the bleeding. In gynaecology, abnormal menstrual bleeding and cramps have been shown to be corrected.

The strengthening of the capillary walls if further observed in the reduction of edemas commonly observed in women who spend a good portion of their days on their feet. Also, high doses of pycnogenol have resulted in a cessation of the bleedings associated with hemorrhoids. No serious side effects have been observed as a result of large doses of Pycnogenol. Dr. Masquelier recommends that in the case of large doses, the doses should be taken at meal-time. "Washing them down" with alcohol is not recommended.

Pycnogenol is highly effective in prevention and therapy of functional deterioration of the liver and other diseases attributed to free radicals such as swollen joints and inflammation, due to alteration of the synovial and collagen deterioration. Pycnogenol's anti-inflammatory activity is based first on inhibition of proteases, enzymes which break down proteins. These enzymes are released inside the body during inflammation. Secondly, it is based on the radical scavenging effect, which is demonstrated in vivo and vitro tests. The Radical Scavenging Effect of pycnogenol can also be applied as a possible adjuvant treatment for many people undergoing radiation and chemotherapy.

From the biological point of view, pycnogenol is characterized by its lack of toxicity. Even in high doses, it is non-teratogenic and non-mutagenic. Pycnogenol is non-antigenic, therefore, non-allergenic. The non-antigen effect of pycnogenol is detected in the biological liquids and tissues by an immunological reaction.

J. Laparra, at the International Bio-Research Institute, tested pycnogenol's non-teratogenic effect on pregnant mice, rabbits and rats, by oral administration of high doses of pycnogenol. The results showed no birth defects on the fetus, and the mother had a normal pregnancy throughout.

Pycnogenol's bioavailability and stability in animals has been demonstrated by oral administration. In man, after the ingestion of 150mg of pycnogenol, the presence of pycnogenol was detected in the saliva in the following hour, which implies the absorption and secretion of non-modified pycnogenol (proanthocyanidin). Pycnogenol was also demonstrated to cross the blood-brain barrier, therefore, its manifold benefits are available to the blood vessels in the brain, thus decreasing the possibility of senility and the incidence of cerebrovascular accidents. The blood-brain barrier is a unique system which regulates the entry of the substances in the brain. Pycnogenol is a very effective protector of integrity of the blood-brain barrier exposed to protein digesting enzymes. Pcynogenol

The Nutritional Benefits of Pycnogenol

by Dr. Arnold Pike, Director
Academy of Nutritional Sciences

Pycnogenol is the trade name for a new potent antioxidant nutrient that comes from the bioflavonoid family of compounds. It can be extracted from grapes, cranberries, beans and other fruits and vegetables but its richest source is from the French Maritime Pine Tree. The discovery of Pycnogenol, perhaps accidental, can be traced to a French explorer over four hundred years ago.

It dates back to 1535 when French explorer Jacques Cartier, on his 2nd voyage of exploration to Canada attempted to sail up what is now known as the St. Lawrence River in Canada. But, this was a trip he would not soon forget. It was winter and Cartier and his men were caught in the frigid snows of Quebec.

Explorer Cartier and his crew tried to survive on biscuits and salted meat, but lacking fresh fruits and vegetables they became victims of the dreaded disease scurvy. Their teeth fell out, some even lacked the strength to walk. About 25 perished before friendly Quebec Indians came to their rescue. The Indians were knowledgeable about the healing properties of trees and herbs and they prepared a tea derived from the needles and the bark of specific pine trees native to the area. Cartier and his men drank the tea and applied the precipitate as a poultice. Within days the remainder of the crew were up and about, their gums stopped bleeding and their strength returned. The tree bark proved remarkably effective. Of course, no one back then knew that pine needles contained vitamin 'C' and that the bark provided an abundance of flavonoids which enhance the body's utilization of vitamin 'C'.

Fortunately, Cartier documented the pine tree incident in his travel log "Voyages Au Canada". Then more than 400 years later French professor Jacques Masquelier, on assignment at the University of Quebec, read Cartier's book and was particularly intrigued by his documentation on how the pine tree saved his expedition from being destroyed by scurvy. At this time Masquelier was deeply involved in his own research on bioflavonoids. He suspected, from Cartier's writings, that this particular tree must be rich in bioflavonoids. Following considerable testing, Professor Masquelier isolated the active components in samples of bark from this unique pine tree. These samples came from the St. Lawrence River area. Upon returning to France, he discovered that the richest source of this highly bioactive substance, called proanthocyanidins (or procyanidins), Pycnogenol's active ingredient, were found in heavy concentrations in the bark of the French Maritime Pine (Pinus Maritima). This tree is found in abundance in the huge Les Landes pine forest in southern France. The extensive research by Professor Masquelier, that led to the discovery of Pycnogenol, was supported and financed by Mr. Charles Haimoff, founder of Horphag Research Ltd.

In October 1992, I met with Mr. Nick A. Mangeris in southern France. We enjoyed a tour of the Les Landes Forest, viewed local saw mills where the bark of the Maritime Pine was being removed and then

BOWEN TECHNIQUE

This incredible technique is currently being taught and practised world wide, with remarkable success. The late Mr Tom Bowen's system is a unique therapy which involves a gentle, dynamic system of muscle and connective tissue moves which realign the body and balance and stimulate the energy flow, empowering the body's own resources to heal itself.

Patients report "feeling" the energy release and flow, and a state of deep relaxation. Treatments are ideally done on soft, low treatment tables and moves are effective through clothing. Sessions can last from 10 to 40 minutes. Relief is often attained after the first session, and some clients only need two or three treatments, usually one week apart. Conditions are treated holistically not specifically, yet there are few conditions which cannot be addressed (with the appropriate medical co-operation). It stimulates circulation, encourages lymphatic and venous drainage, promotes assimilation of toxins, increases joint mobility and improves posture. Excellent results are reported from those with sporting injuries, back aches and pains, joint discomfort, bronchial, urinary and female problems.

Many licensed health care practitioners around the world are now using the technique and are full of praise for the amazing results. Bowen's gift was discovering the dynamic system of moves that reinstate natural flow, restoring the structural and therefore the functional integrity of the body, and thus keeping nature in balance. The key to the technique's success is its holistic action.

POLARITY THERAPY

This is a concept of energy, bodywork, and a composite healing philosophy based on East Indian Ayurvedic principles. Created by Dr. Randolph Stone, an osteopath, chiropractor, and naturopath, polarity is designed to balance the body's subtle or electromagnetic energy.

The main techniques used are touch, working with polarity trigger points, stretching exercises called 'polarity yoga' or 'polar energetics', an approach to eating and nutrition based on the philosophy's principles, and attitude and mental-emotional balancing.

Unlike other bodywork techniques, Polarity Therapy does not manipulate muscles or bones but works through the body's own energy system by placing hands on the body's energy centres to redirect the flow. Polarity therapists see the body as a core magnet that generates an energy field around it. When the energy currents are blocked or impaired, the physical, mental, emotional, and energetic levels of the body lack the balance and strength to nourish the whole being and stress, pain and illness can result.

Energy manipulation by touch is the main technique, however it's not the only focus. Adjustments made in the current flow will not last if poor habits are maintained - in nutrition, exercise, and thought. Exercise is part of the total approach.

KINESIOLOGY

This technique was developed by the American chiropractor, Dr George Goodheart. Derived from the Greek word kinesis which means 'motion', it combines muscle-testing with the ancient principles of Traditional Chinese Medicine to diagnose the energy levels of the individual and where the energy is being blocked.

The technique itself employs a range of gentle yet powerful natural healing techniques to improve health and increase vitality. Kinesiology can address any number of symptoms because it balances the whole body and puts it in the most optimum state to heal itself.

Kinesiology is useful for a variety of disorders, from headaches to PMS.

It is a relaxing and effective system to help achieve wellbeing.

THE DEVELOPMENT OF OXICHEL®

by Dr WD Raymont. Ph.D., M.A.C.S., M.N.Y.A.S., D.G., O.I.A.

OXICHEL® is a highly developed and powerful antioxidant, vitamin, mineral and herbal dietary supplement with a total of 32 ingredients. This product is patented and is licensed exclusively to Herbal Dynamics on a world-wide basis.

VITAMINS:

The vitamins and minerals in OXICHEL® have been selected to provide the most advantageous combination and quantity of each restricted only by some national (Australia and New Zealand) Regulations. Particular attention has been given to the NH&MRC RDI of each and particular emphasis has been placed upon recognised international research published in recognised scientific and medical journals.

Reduction of Cancer Risks

Recently completed long-term studies have shown the antioxidant vitamins A, C, E and Beta-Carotene (Provitamin A) to have significant effects in reducing the incidence of cancer.

A major study was conducted over a period of five years on 30,000 residents of the Linxian region of Northern China where stomach and oesophageal cancers are 100 times more common than in the USA. The results of this study were published in the Journal of the National Cancer Institute. The 15,000 residents who were given a cocktail of Beta-Carotene, Vitamin E and Selenium (Selenium is a Schedule 4 prescription drug in Australia) showed a reduction in cancer-related deaths of 13%, a reduction of 9% in overall deaths and a 21% reduction is stomach and oesophageal cancer.

In Finland, Dr Jussi Huttunen, the Director of the National Public Health Institute, released the results of a study on 29,000 smokers who were given a daily supplement of 20mg Beta-Carotene and 50mg Vitamin E. These results have been published in the New England Journal of Medicine and show a substantial reduction in lung cancer.

Dr Gladys Brock of the University of California in Berkeley researched 170 scientific dissertations on vitamins and reported that 132 of them attested to the efficacy of vitamins against cancer. Professor Jürgen Wahrendorf of the German Cancer Research Centre in Heidelberg reported that Dr Brock's research demonstrated reductions in cancer risks by up to one half.

An eight year study of 90,000 nurses by researchers at Harvard University in Boston showed that nurses with a dietary deficiency of vitamin A suffered a 20% higher incidence of breast cancer.

Currently, worldwide, there are over thirty long-term studies of the anti-cancer effects of vitamins underway and one of the greatest advocates of antioxidant vitamin supplementation would be 93 year old Nobel Laureate Professor Linus Pauling.

Chelation of Cholesterol Plaque From Arteries

The relationship between trace residues of the heavy metal, cadmium, and arterial deposition of cholesterol is well documented and was first proposed in the 1960's by Professor Harry Bloom of the University of Tasmania. Extensive research by WHO in the late 1970's, in which the writer took part, confirmed this relationship beyond any reasonable doubt.

Considerable success in the chelation of the cadmium metal from this cholesterol plaque, thereby re-dissolving the cholesterol, has been reported from regular massive intravenous infusions of EDTA and/or vitamin C but clearly, less invasive methods would be much more desirable.

Over recent years, more and more evidence is coming to light that the antioxidant vitamins can fulfill this role to a greater or lesser extent. Not only have they been shown to have efficacy in the chelation above, but also in the inhibition of LDL oxidation.

Certainly, the presence of free radicals has been well accepted as the cause of much cardiovascular disease, especially atherosclerosis. Equally well accepted is the role of antioxidants in combatting free radicals and thereby preventing, controlling or even reversing such disease. Antioxidant vitamins also have reported efficacy in the reduction of hypertension.

Further reading

Perhaps one of the best and most comprehensive reviews of the function and health effects of vitamins in recent years is

in the Annals of the New York Academy of Sciences, Volume 669, entitled *Beyond Deficiency* (ISBN 0-89766-750-6, $US125.00) with five papers each on the Cardiovascular and anti-cancer benefits of vitamins (with 337 and 279 references respectively).

HERBAL ANTIOXIDANTS:

Some of the most significant advances in recent years have been in the field of herbal antioxidants. One proprietary product receiving much publicity at the moment is Pycnogenol®, the Registered Trademark of Horphag Pharmaceuticals of Guernsey, U.K. This product is a proanthocyanidin concentrate; proanthocyanidins are sometimes referred to as leucocyanidins, bioflavonoids and polymers of catechin.

Proanthocyanidins are naturally occurring antioxidants which are claimed to be up to fifty times more powerful than the antioxidant vitamins and to have much more effective bio-uptake. The major disadvantage of concentrates of these substances is the prohibitive cost - up to $US3,700 per kilogram!

However, cost has had to become a secondary factor in the formulation of **OxiChel®** as, with its formulation, a commitment was made to produce the best and most effective antioxidant combination practicable and, as a result, proanthocyanidin concentrates represent some forty milligrams of the formulation of each tablet. Concentrated extracts from red grape seed, bilberry fruit and lime flower have been formulated to provide the maximum quantity and bio-availability commercially feasible along with twenty-five milligrams of bioflavonoids in each tablet.

Ginkgo extract has been included to potentiate the absorption of the proanthocyanidins and leucanthocyanidins and because of its documentation in herbal medical texts as a circulatory system stimulant.

Echinacea extract is similarly well documented as an immunostimulant, anti-inflammatory and antibacterial.

The therapeutic claims for **garlic** need no re-iteration and **parsley** has been included to contain the odour of the garlic.

MINERALS:

Nine essential dietary minerals have been included to supplement normal dietary intake but sodium and phosphorus have been avoided as both of these are present in excess in normal diets. Furthermore, selenium has also been avoided as this is a prescription drug in Australia.

DOSAGE:

One or more tablets twice daily depending upon age and state of health. Therapeutic doses of three tablets three times per day can be directed by health care professionals.

TGA:

OxiChel® is listed on the Australian Register of Therapeutic Goods as a non-prescription pharmaceutical product (AUST L54069).

EACH TABLET CONTAINS:

BETACAROTENE	2.0mg
THIAMINE HYDROCHLORIDE (VITAMIN B1)	500µg
RIBOFLAVINE (VITAMIN B2)	800µg
NICOTINAMIDE	25mg
CALCIUM PANTOTHENATE (VITAMIN B5)	50mg
PYRIDOXINE HYDROCHLORIDE (VITAMIN B6)	1.0mg
CYANOCOBALAMIN (VITAMIN B12)	1.0µg
ASCORBIC ACID (VITAMIN C)	200mg
CHOLECALCIFEROL (VITAMIN D3)	6.1µg
D-ALPHA-TOCOPHEROL (VITAMIN E)	21mg
BIOTIN	30µg
FOLIC ACID	75µg
CALCIUM (AS AMINO ACID CHELATE)	10mg
CHROMIUM (AS CHROMIC CHLORIDE)	10µg
COPPER (AS GLUCONATE)	10µg
IODINE (AS POTASSIUM SALT)	15µg
IRON (AS AMINO ACID CHELATE)	2.6mg
MAGNESIUM (AS AMINO ACID CHELATE)	5mg
MANGANESE (AS AMINO ACID CHELATE)	1.0mg
POTASSIUM (AS GLUCONATE)	10mg
ZINC (AS AMINO ACID CHELATE)	1.6mg
BIOFLAVONOIDS	25mg
CHOLINE BITARTRATE	25mg
CYSTEINE HYDROCHLORIDE	50mg
INOSITOL	25mg
VITIS VINIFERA (GRAPE) SEED EXTRACT	
EQUIV DRY SEED	1.8g
PETROSELINUM CRISPUM (PARSLEY)	
HERB DRY	30mg
ALLIUM SATIVUM (GARLIC) EXTRACT	
EQUIV BULB DRY	35mg
VACCINIUM MYRTILLUS (BILBERRY) EXTRACT	
EQUIV FRUIT DRY	500mg
ECHINACEA PURPURAE (ECHINACEA) EXTRACT	
EQUIV ROOT DRY	100mg
TILIA CORDATA (LIME) EXTRACT	
EQUIV FLOWER DRY	70mg
GINKGO BILOBA (GINKGO) EXTRACT	
EQUIV LEAF DRY	60mg
TABLETTING AIDS (NZ)	

Also contains sucrose as an excipient in proprietary ingredients (less than 5mg per tablet)

Contains no added artificial colours, flavours, sweeteners or preservatives and no gluten, yeast, rice, wheat or corn.

CONCLUSION:

OxiChel® provides the user with the most comprehensive and synergistically formulated antioxidant, vitamin, mineral and herbal dietary supplement possible at a realistically affordable price.

Detoxification:
A Vital Step Towards Becoming Healthier

Toxins

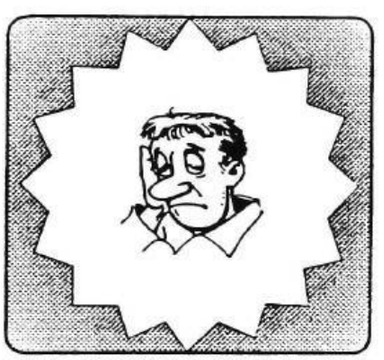
Leslie Kenton, in her popular little book, "The 10 Day Clean-up Plan" wrote that, "beautiful skin, a firm and healthy body and a clear mind are strongly dependent on your system being able efficiently and effectively to get rid of toxic materials and the waste products of your bodily metabolism before they have the chance to do damage to cells and tissues, organs and systems. This principle forms the foundation of the long European tradition of natural medicine: Remove whatever obstructions to rapid and near-complete elimination there may be present in the body. Then, thanks to the natural laws of self-healing by which living organisms appear to be constituted, bodily functions will tend to return to normal."

"...The human body is magnificently designed to cleanse itself automatically without any thought ever needing to be given to the process. The trouble is that the kind of food and drink most people in the West put into their bodies, the tendency we have to lead stressful but sedentary lives, and the increasing number of pollutants to which we are exposed through the air we breathe and the water we drink have created a situation in which often far more toxins are taken into the body, and far more metabolic wastes produced by it, than we can effectively get rid of. They are stored in the tissues where they lower vitality, encourage the development of degenerative diseases and early ageing, and rob your system of nutrients necessary to keep your skin and hair - indeed, your whole body - looking their best."

"Dr Dwight McKee, Medical Director of the International Health Institute in the United States believes, as do a growing number of doctors ... that our cells are literally chock-full of metabolic and environmental wastes gathered over a lifetime. To live at a high level of health and vitality and to make the most of our potential for good looks we need to get rid of them."

The Effect of Toxins

Toxic accumulations in the body create an environment in which it becomes easier for disease to develop. As toxins increase within the body, proper oxidation cannot take place in the tissues and the body is unable to properly replenish its cellular structure and the excretory organs such as the skin, liver, kidneys, lungs and lymphatic system are unable to cope with the increased workload being placed upon them. The functioning of these organs becomes erratic and unreliable. Cellular metabolism becomes sluggish, repair and growth are delayed and the ability to eliminate waste is lowered. Cells within the body begin to die or become inactive.



Even though we are not feeling our best, it is a good sign ... we know that somewhere inside restoration has begun and soon we will be the healthier for it...

What is "Detoxing"?

Detoxing has been described as the body's "Spring-cleaning". For example, certain herbs and other foods can bring about a natural cleansing inside the body which allows the body to take in fresh nutrients and to revitalize itself. As this happens toxins which have accumulated, perhaps over many years, begin to be released.

Sometimes as this happens, the body experiences symptoms such as headaches, tiredness, bad breath or body odour, swelling in the body, slight skin irritations, aches and pains in joints and body, or perhaps slight nausea. We might even imagine that whatever we have taken has actually made us sick.

But this is almost always a good sign: somewhere inside us something is finally happening which will help us and eventually bring about a restoration. Usually, such discomfort will only be minor, lasting only a few days at most, and will not greatly interfere with our daily routine. However, some folk with particular medical problems may experience quite severe headaches and other reactions as their bodies undergo a cleansing.

In her book "The Biogenic Diet", Leslie Kenton writes, "Very occasionally when someone goes on an active programme of detoxification such as the biogenic diet or - even more so - the applefast, he or she has the experience of a severe headache at some time within the first three days or of feeling moody or of having an upset stomach or loose bowels. This is a sign that your body is throwing off wastes at such a pace that you are experiencing what is known in natural medicine as a "cleansing crisis". In fact it happens to very few people. If you are one of them be glad - even though it may be a bit of a nuisance for a few hours, it is actually a good sign. Your body is taking the opportunity you have afforded it through what you are eating (and what you are *not* eating) to throw off a lot of debris which you need to get rid of if you are to shed unwanted fat permanently and live at a higher level of health and vitality."

"People most likely to get a headache as part of a cleansing crisis are those who have been drinking several cups of coffee a day. This kind of reaction is triggered by your tissues dumping a lot of stored caffeine into your bloodstream all at once in order to eliminate it from your body."

Our own research is showing that some people who have commenced taking **Herbal Dynamics'** powerful new antioxidant product **OXICHEL®** (AUST L 54069) are experiencing this type of "detox", as the combination of herbs and proanthocyanidins in the product appears to be far more effective in ridding the body of toxins and free-radicals than products they previously were taking. Many, having continued with the product, also have commented on the additional energy that has followed.

Antioxidants Help

Leslie Kenton writes, "Antioxidants are nutrients - such as vitamins A, C, E, some of the B complex, beta-carotene, zinc, selenium and some of the sulphur-based

amino acids - which help protect living systems from the free-radical damage that occurs when the body has a high burden of toxicity or is exposed to radiation.

Free-radicals are formed in your body in a variety of ways. Some are simply by-products of normal metabolic processes. Others come as a result of radiation damage arising, for instance, through exposure to the hazards of low-level nuclear radiation in the environment or electromagnetic emanations from equipment such as video-display units of computers or even the ultraviolet rays of the sun. Still others are created through the process of peroxidation whereby the fats or lipids in your body react to form chemical compounds known as peroxides. Whatever their origin, free-radicals create toxicity in the system - toxicity which can encourage the laying-down of fat-stores, damage to cells and cell parts, lowering of vitality, cellular pollution, and interference with the healthy metabolic functions which make high-level well-being possible.

Antioxidant nutrients, as noted, help protect your body from free-radical damage. They are master detoxifiers. Each antioxidant has a specific action on your body. For instance the water-soluble nutrients such as Vitamin C help protect your body's water-soluble molecules while the oil-based cell membranes in the body get better protection from a fat-soluble antioxidant such as Vitamin E.

But these antioxidants - which you take in through the foods you eat and which are also available in higher levels in the form of nutritional supplements - all work in *synergy*. That is, they work together, with the actions of each supporting the actions of many others. And it is the multiple interactions of nutrients - never their single actions - which make them biologically efficient in detoxifying your body and in restoring normal metabolism."

And this is why we believe that broad spectrum, synergistically balanced products like OXICHEL® will give better results than the individual ingredients taken as separate supplements. OXICHEL® also includes proanthocyanidins from at least *four* different sources, greatly increasing its potential in countering the effect of free-radicals.

Leslie Kenton continues, "Taken three times a day with meals for a few months, a good nutritional formulation of antioxidants together with a full range of other vitamins and minerals with which they work may be of real help to [many people]. It can hasten the detoxification process of the body. It may also speed the process of restoring nutritional support to the metabolic machinery so that it starts working at peak ..." (Pages 97 & 98, *The Biogenic Diet*)

What can we do to help?

To encourage elimination, there are two areas where we can do more to assist:

The kidneys:

To help the kidneys it has been suggested that one could drink a litre of parsley tea each day. One "recipe" is as follows:

Parsley Tea

Place a bunch of parsley in 1 litre of water. Bring to boil. When boiling turn stove off. Let stand for 10 minutes. Strain. Drink tea during the day, either warm or cold.

The bowel:

To help the bowel cope with the extra waste being produced take one tablespoon of Milk of Magnesium (available at most health food stores) every hour until your bowel movements are diarrhoea. Then cut back to one tablespoon three times a day, or until you find what suits your body.

Other ideas...

For headaches:

Milk of Magnesium will also help with headaches.

For joint aches and pains:

First thing in the morning before anything else, have a glass of warm water with half a lemon squeezed into it.

For skin irritations:

Make a cup of camomile tea, let it cool, then bathe the area affected using cotton wool (or similar) to spread the tea.

Remember...

Sickness and disease do not usually happen overnight but are the result of possibly years of wear and tear upon our bodies. Nor can they usually be *corrected* overnight or even within a few days. But entering a period of "detox" is a guarantee that our bodies are busy repairing and restoring.

The Lymphatic System

"There are five main eliminative routes in your body - the skin, the lungs, the kidneys, the bowels and the lymphatic system.

None of them is less generally recognized or more important in spring-cleaning the body than the lymphatic system. Yet the state of its health and functioning is still almost completely ignored by most people. Your lymphatic system is not only a major route for the absorption of nutrients from the digestive system into the tissues - which helps keep skin healthy, youthful and glowing - and an important carrier of immune cells which guards your body from damage and illness and prevents degenerative ageing, it is also your body's metabolic waste disposal system. Carrying unwanted proteins and large particles of waste matter which cannot be removed by any other means away from your cells and tissues, it clears away toxins - the by-products of fatigue and of stress, dead cells, fatty globules, pathogenic bacteria, heavy metals, infectious viruses and other assorted debris which your cells cast off. So essential are the waste-eliminating functions of the lymphatic system that without them you would die within 24 hours." Leslie Kenton, *The 10 Day Clean-up Plan.*

Anyone wishing to read further on this subject is encouraged to read Leslie Kenton's books, "*The 10 Day Clean-up Plan - Detoxify Your Body for Natural Health and Vitality*" (Century Hutchinson Ltd, London, 1986, ISBN 0 7126 1029 4) and "*The Biogenic Diet - The Natural Way to Permanent Fat-Loss*" (Arrow Books, London, 1986, ISBN 0 09 950740 4).

The Natural Remedies Information Group

We are a voluntary group dedicated to improving one another's quality of life. We have no joining fees or subscriptions and no affiliation with unprincipled marketing gurus. We hold regular meetings to keep our members and other interested persons up to date with anecdotal, as well as technical and research, material.

If we can help further in any way, please do not hesitate to contact one of the following members or the person who gave you this sheet.

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Evening Primrose Oil

Can Therapeutic Claims be Justified?

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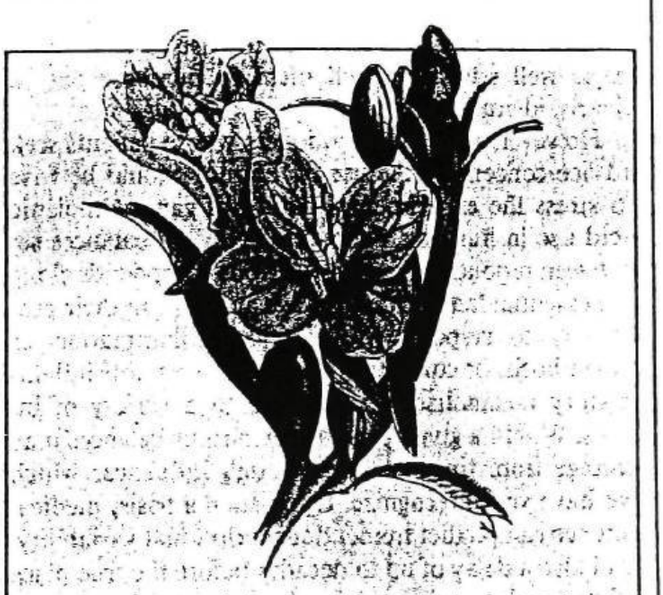
Things were much easier for William Withering studying the foxglove in the late eighteenth century than they are for today's medical practitioners and clinical scientists investigating the virtues of the ancient general panacea, 'King's cure-all', *Oenothera biennis*, or evening primrose. Withering had a single source for his basic information, the media did not exist in their modern form, and he did not have to concern himself with the properties of individual glycosides versus the effects of the gypsy's infusion. Some things have not changed since the eighteenth century, however, notably the human propensity for superstition and belief in magical practice, and the concomitant distrust of the scientific method with its slowness in terms of unravelling the mysteries of chronic diseases. Moreover, there is an evocative, glamorous and soothing overtone to the name 'evening primrose oil', and even the chief constituent of interest, gammalinolenic acid (GLA), has an impressive title.

Gammalinolenic Acid and Fatty Acid Metabolism

The starting point for resurgence of medical interest in evening primrose lies in theoretical biochemistry. Abnormalities of essential fatty acids (EFA) intake and absorption are extremely rare despite the diversity of human diets, but there has been evidence for some time that aberrations of essential fatty acid pathways might underlie a number of metabolic disturbances in a series of chronic diseases.

Life as we know it depends upon membranes which provide the basis for spatial ordering and thus for chronological sequencing of chemical events. Essential fatty acid metabolism must function efficiently in order to preserve the balance of essential lipid components in outer cell membranes and intracellular membranous structures. Abnormalities of essential fatty acid metabolism are demonstrable upon a genetic basis, e.g. in atopy, and they also appear as secondary phenomena, e.g. in diabetes or alcoholism. It is possible that the effects of ageing and of altered balances between dietary constituents may affect the relative levels of activity along the essential fatty acid pathways [1,2]. All essential fatty acids are polyunsaturated and their metabolism follows one of 2 pathways (fig. 1). The so-called n-3 pathway derives from the biologically inactive precursor alphalinolenic acid, the n-3 notation being derived from the position of the first double bond from the omega end of the fatty chain. The evening primrose oil story is concerned with the n-6 pathway which starts with cis-linoleic acid.

Prostaglandins and leukotrienes are the technical terms applied to some short-lived, highly reactive molecules which derive from these 2 metabolic pathways. The PG_1 series of prostaglandins, produced by the n-6 pathway, dilate blood vessels, and inhibit both inflammatory reactions and platelet aggregation. More peripherally along the n-6 pathway, however, one branch of the sequence leads to production of leukotrienes which stimulate inflammation and cause smooth muscle spasm. At this end of the pathway thromboxane A_2 is produced and this molecule also induces vascular spasm, thrombosis and inflammation of blood vessel walls. The relationship of leukotriene metabolism to obstructive airways disease is



[Illustration prepared by ADIS Press.]

thromboxane derived from endogenous arachidonic acid, can be explained as a result in a fall in cyclic AMP resulting from reduced production of PGE_1 from dihomogammalinolenic acid. In the presence of cyclic AMP, there is inhibition of mobilisation of arachidonic acid from phospholipid stores [4]. To date, no trials of gammalinolenic acid in diabetes have been reported.

Evening Primrose Oil in Perspective

There is a small but increasingly impressive set of publications on essential fatty acid metabolism which is consonant with the basic theory proposed by Horrobin and others, and there is sufficient experience with preparations such as 'Efamol' to indicate that consumption is probably harmless, particularly while the cost remains high and gross overconsumption is therefore unlikely! Others beside William Withering have provided historical precedents demonstrating that significant therapeutic advances can precede understanding of intermediary metabolism. Ethically motivated optimists amongst the ranks of medical practitioners, who link this historical fact to the 'first do no harm' precept, can produce a case for counselling patients to try gammalinolenic acid for management of various chronic conditions for which orthodox medicine lacks any effective remedy. Practitioners who favour such a philosophy should advise patients not to consume vast quantities of any polyunsaturated fatty acid preparation such as 'Efamol', because there are theoretical reasons why high levels of consumption might, paradoxically, accelerate ageing or even be carcinogenic. These are areas of ignorance and counsels of moderation should prevail.

Another group of practitioners can, for equally valid philosophical reasons, point to the vast numbers of therapies which have had a seemingly rational basis but which have fallen by the wayside. These doctors may prefer to counsel their patients to save dollars and cents, to follow the New Zealand nutritional guidelines, and thus to consume a wide variety of foodstuffs in amounts which do not upset energy balance. In any event, advice should be tailored to the patient and his or her family circumstances, with due regard to psychosocial factors and the usefulness or otherwise of the placebo effect [22]. Whatever the outcome 20 years from now, the work stimulated by Dr Horrobin and others will be seen as a major contri-

Experience shows

A pH level over 7.56 sets the stage for the development of tumours *(Fasching)*.
It might be confusing, but acid food (pH less as 7) has an alkaline effect in the body.
There are two groups of acid and alkaline foods.
One is the acid or alkaline foods and to the other is the acid or alkaline *forming* foods. This reversing effect of the second group leads the wrong conclusions. For example the lime is extremely acid with a pH reading of 1.9. But this fruit increases the alkaline in the body. If someone wants to influence the body's pH it is not so important to know the pH of the particular food it self, but the reaction in the body of that food.
For more information it is recommended to study the book: "Acid and Alkaline" by Herman Aihara.

Interesting in this context are researches from Russia and Czechoslovakia.
Water is divided into "live water" and "dead water."
DC current converts neutral water of about pH 7 into acid water (pH 4) and alkaline water (pH 10).
This water is used according to reports against all possible diseases with excellent results. The research was based on the fact that plants can thrive only in a specific pH milieu. Unwanted stinging nettles for example can be eliminated in two ways. One is to spray with chemicals with the negative environmental side effects. The other is to alter the pH of the soil (calcium) so that the stinging nettle can thrive no longer.
Its similar with diseases according to the research. Altering the pH of the blood should fight certain diseases. With cancer for example, if the blood pH is altered with activated water to 7.4 there is no "fertile soil" for the cancer which should prevent further growth of the tumour.
As the information from Russia shows, over 500 patients with different diseases where all treated with success.
It is also pointed out however, that it is impossible to cure all diseases with this water. *(Krotov)*
The manufacture of this water is relatively easy. I have met in the last months some persons from Czechoslovakia, all confirming with enthusiasm about the healing successes with activated water.
You find detailed information about "live water" and "dead water" in my book about water-cures.

How to brew your own Kombucha.

Ingredients:

- 2 litres of water
- 160 grams of sugar (about 12 table spoons)
- 6 grams tea (2 tea bags)
- 1 healthy Kombucha culture
- 100 ml. (1 cup) Kombucha fermented tea.

Heat the water.
Pour 160 grams of white sugar (app. 12 table spoons) into the heated water until dissolved.
When the water boils, remove from the stove and add the tea.
Either black or green tea: 1 to 2 tea spoons (or tea bags) - leave for 10 to 15 minutes.
or

Alternatively use a herbal tea (please remember, do not use a tea that contains oil) :
2-3 tea spoons of herbal tea, leave for 5 minutes.
Strain off tea leaves (or remove tea bags).

Cool the tea until luke warm and pour into a glass, porcelain or pottery container (see also chapter *The brewing pot*).
Add app. 1 cup (10 %) of an already fermented Kombucha beverage together with the fungus.
The fungus will usually first sink to the bottom at the beginning of fermentation.
Close the lid with a piece of cloth which allows to let air through, fasten it with a rubber band. This ensures that no insects can get into the fermentation container. The container should be stood in a warm place (ideal fermentation temperature is between 23 and 28 degrees C.). The fungus does not require any light.
An important feature is that the fungus requires warmth and air. Smoke is harmful.

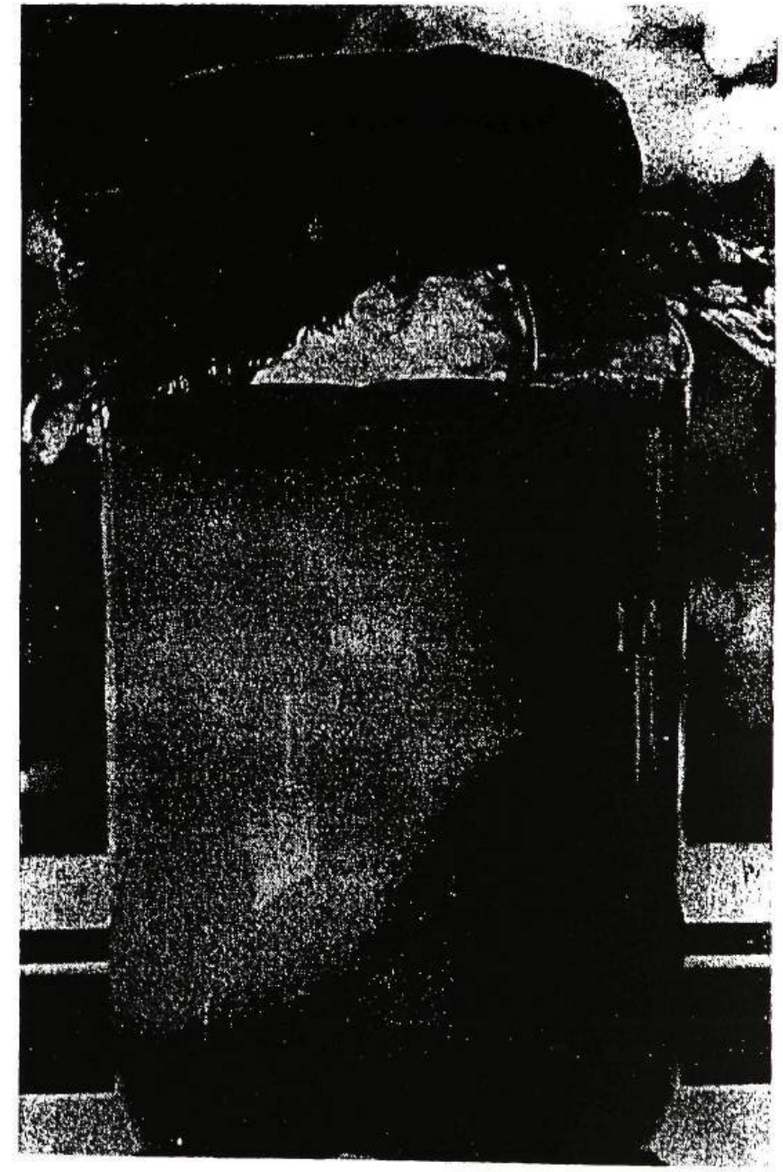
After 8 - 10 days of fermentation, remove the fungus with clean hands, strain the beverage and fill into bottles.

The **bottles** should be placed in the fridge, otherwise the fermentation process will continue and the beverage will obtain a sour taste.
With the **fungus** a new batch can be started immediately. When a new fungus has grown on top of the liquid, it can be parted, using a clean pair of scissors so that several batches can be started at the same time.
If no batches are started on the same day, the fungus can be kept by placing it into an air tight container with some Kombucha beverage and keeping it in the fridge.
It is recommended to drink 3 glasses daily, (each 00 - 200 ml), one prior to breakfast and one with or after each meal. Larger amounts can also be consumed.
There are no limitations for the Kombucha brewer, the more experienced he gets, the better the result is likely to be - Cheers to your health !

The brewing pot

The most suitable containers for brewing are glass, porcelain or glazed pottery.
Metal containers are not used because acids in the brew react. The brew in stainless steel containers does not taste as good as in common containers. This might be like with whisky or wine which taste different when fermented in wood.
Plastic is more and more commonly used. It should be high quality food grad, acid resistant containers. Polyvinyls, polypropylenes and cheap plastics can cause chemical reactions in the brew. Beer brewing containers used for home brewing can be used.

The containers should have a wide opening not be too high (or not filled up to the top) so that not too much volume of tea is beneath the culture with not enough surface area for it to grow quickly. A wider more shallow pot ferments quicker and better.



Fermentation in a two litre glass jar.

APPENDIX C

Concerns of people with MS

Subject (1-40) concerns made in open ended questions:

1. Transport difficult to find parking spots, Carers Network to support each other, home access and preparation for worsening disability in future, cost of living generally very high for pensioner, MSSQ very helpful and supportive, medical tests too expensive and no monetary return for MRI
2. Need free medical equipment eg catheters etc as the allowance is not enough for the whole year.
3. Wants refund on Naturopathy and other complementary medicines refund on MRI when diagnosed, would like more information on complementary therapies
4. More counselling services should be available at any time of the day or night
5. Very content with services really nothing else they want
6. Would like case managers to have holistic approach, assistance with shopping friend to help with the chores. More cohesive programme to link all services. Complementary services should have obligation to clients for linking with other medical practitioners and should not lead to dependency on a particular treatment regime. She is 'cynical, angry and broke'.
7. Local doctors should be better educated about MS as they know very little. More public awareness about MS as people don't understand about the tiredness. Also dislikes the comparisons everyone makes between people with MS. 'We are all different'. Would like to get information in a more

positive environment. More and easier access for people with ms and transportation - roads, ramps and parking

8. Feels that the services have improved and that there is more offering than before for people with MS.
9. Content with everything as it is
10. Would like access to physiotherapists within the home community rather than having to access the MSSQ physio - too far Would like home help and transport assistance more parking and people to assist in shopping. Would like more awareness of the disease amongst health professionals especially GPs and physiotherapists. Need more carer support networks and need a geographically separate place from the mssq as it scares some people. Maybe in community health centres.
11. Someone to write cheques and lists for her and also the continuing cost of maintaining the scooter someone to pay for repairs. Need wheelchair for outings with friends.
12. Content with the services available.
13. Family does not want to know about the disease and this leaves her isolated and feeling that she is faking the disease. Not even husband, mother in law is sympathetic
14. Need advice prior to purchasing equipment as expensive and difficult to procure. Government refuses to assist if have assets. Community nurses wonderful. Feels MSSQ does not want people to come if they have money to access private help. If waiting in hospitals should have better facilities

while waiting to see health providers. Would like to tap into superannuation but can't without tax penalty. Government resources not helpful as have insufficient advice, insufficient and incorrect advice about equipment.

15. Sceptical about what services are provided - nothing works and there is no use in accessing anything. Would like to see alternative therapists have some sort of validates certificate so not quacks and patients can know who to trust and not get ripped off. Support from the Housing commission is good and helpful. Traditional and non traditional practitioners are antagonistic to each other and should work together for the good of the patients.
16. Feels main needs met however found it hard to know who is a good neurologist - would like a list of recommended neurologists interested and good at treating ms. Also trying to find supportive and helpful general practitioners is a challenge.
17. Everything OK at moment and gets home help 4 hours a week paid for. Information from the mssq is too confusing and really she doesn't want to know all the bad news. Also still driving but she should give it up as too bad but worried about alternative with transport - how to get around. Frustration in activities of daily living and relies on her 10 year old daughter to cook and help around the house.
18. OK with things but cost of incontinence pads are expensive and only a $500 yearly limit which should be increased. Need more subsidies.
19. Need heated pool close to home for hydrotherapy and having the disable parking sticker is absolutely wonderful!!! Likes taking complementary

therapy as she is in control of her MS. However finds ms very depressing and feels guilty because she is not as bad as everyone else with MS. She has fear of ending up like that she doesn't like getting information from the MSSQ etc. stays separate from other people with ms.

20. Access points for some service industries do not have entrances for disabled people. Also she is not aware of all the services available for people with MS and would like some proactive information given to medical practitioners to educate them Some of the tests for MS are very debilitating and depressing.
21. Feels that people in the outer areas of Brisbane and regional areas of Qld miss out on some services. When he needs braces for his legs he must travel to city for the service.
22. Would like easier access to information and better support network for carers. Transport to Brisbane is costly and problems with bowel and bladder can be awkward in the plane or bus. Would like more information about adl skills put into place in regional areas. Also, when diagnosed would like information on potential problems for people with MS. Children of parents with MS need to understand the issues involved.
23. Would like GPs better educated and also local health facilities when you don't live in Brisbane city. Need a good physio who is close to the regional centres. In local areas outside of main cities there is very little education and awareness about ms and the needs of people with ms. When diagnosed it

would be useful to have phone numbers of services and providers for people with MS.

24. Uses the hydrotherapy pool in local community and joined a group of other people with disabilities. Has great support and feels that both family and friends are supportive.

25. Would like easier access for public toilets and wheelchair access to shops and facilities. Better car parking would be appreciated.

26. Didn't like going to the mssq because everyone in wheelchairs and it was frightening. She would like two groups where less disabled people could not be frightened.

27. Happy with status quo. Has supportive wife and is happy with DSS, hospital, etc.

28. Feels services are adequate and doesn't want anything else at the moment. MSSQ good for moral support.

29. Mobility allowances very restrictive. Feels there is a lack of information about MS for the carers. Would like access to up to date information about MS research and treatments and services .

30. No complaints - has access to taxi vouchers and managing well. Everything has improved now when compared to years ago. Would like home help for washing.

31. No availability for services in regional centres. Transport for getting to physio of other services very expensive and time consuming. Wants local

services... Would not go to mssq and believes in helping myself. need help for carers who look after people with bad disease.

32. Things are OK. Has had good support from local nurses and has taxi vouchers which help with the transport.

33. Too far to access MSSQ in Brisbane city - would like regional help. Family members of people with ms need special consideration and a social worker is necessary to discuss some of the issues and how to resolve. Also a multidisciplinary clinic would be good idea so that holistic help is forthcoming.

34. Lives in outer suburbs and MSSQ too far to travel to. Would like to chat and meet with others. Enjoys meeting with others in the support group for MS.

35. Happy and does not need any help

36. Often is very depressing in support groups. When on holidays it is very difficult to get suitable accommodation for wheelchairs. Toilet facilities when travelling are not good. GPs are not educated about MS and are not aware of the issues involved. They need educating.

37. Transport can be a problem. Prefers to stay away from others with MS as they are too morbid and better to get on with life. Husband works therefore she does not qualify for home help - unlucky. Husband works therefore no help from government.

38. Satisfied with services at present time. Has supportive family.

39. Carers need more support both emotionally and monetary. Need to know about tax exempt items and how to acquire things for daily life improvements. GPs are not educated about MS and need to know more

also physiotherapists and other health professionals need information on MS. Quality of health professional varies dramatically from person to person.

40. Transport issues are difficult but feels that has adequate support and help.